UNIVERSITY OF ALBERTA

JUSTIFYING THE REFUSAL OF BREAST CANCER THERAPY

BY

LOUANNE PATRICIA KEENAN

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in partial fulfillment of the requirements for the degree of

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Louanne Keenan

1042 Parker Drive
Sherwood Park, Alberta
T8A 1C6

Dated: April 15, 2002.

UNIVERSITY OF ALBERTA

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled JUSTIFYING THE REFUSAL OF BREAST CANCER THERAPY submitted by LOUANNE KEENAN in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY

Dr. Nancy Gibson (Supervisor)

Dr. Vangie Bergum

Dr. Brenda Munro

Dr. Karin Olson

Dr. Priscilla Koop

Dr. Margaret Kearney NK
Dr. Margaret Kearney (External Examiner)
Boston College School of Nursing

Date: 14 April 2007

DEDICATION

This thesis is dedicated to my Jeremy, Andrew and Daniel:

Who accompany me on this life journey.

IN MEMORY OF

The young women who have gone from this world, but not from my heart:

Mary, Devinder, Karen, Trudy, and Joanne.

ABSTRACT

The process of making treatment decisions by women confronting breast cancer (also referred to as breast carcinoma), reflects their pre-established preferences for traditional biomedical therapies and/or alternative interventions, and their expectation for successful treatment and a long disease-free life. The objectives of this study were (1) to identify the internal and external issues inherent in the decision making process experienced by women who modified or refused prescribed breast cancer therapies, and (2) to describe the context within which the process occurred.

The grounded theory qualitative method was used to study the decision making process. During open-ended, semi-structured interviews, the women were encouraged to describe their decision making experiences. Seventeen women who had refused adjuvant breast cancer therapies for stages I - III breast cancers, were selected from community contacts and referrals from health care providers. Theoretical sampling was used for the purpose of theory development. Only subjects who had completed breast surgery (mastectomy or lumpectomy) were included, since stage of disease and treatment plans are determined by surgical and pathological findings. Participants ranged in age from 37 to70 years, with the mean age of 52 years. Interviews took place either in the women's homes or at their offices after work hours and lasted between 1 to 3 hours.

Audiotapes of the interviews were transcribed, and the resulting narrative material was sorted and coded according to the constant comparison method. Each transcript was read and coded several times until a category could be named

and described with confidence. Then the data were entered into the NUD*IST 4 software for additional line by line coding and definitive qualitative data analysis. The women formulated their decisions according to their pre-established preferences for traditional medical therapies and/or alternative interventions. Four indicators accounted for variations in decision behavior: 1) modification (choosing some but not all of the prescribed therapies), 2) persuasion (agreeing to some but not all medical and complementary treatments), 3) conviction (opting for only alternative interventions), and 4) omission (declining all further treatment). The justification process was reviewed within an ecological framework to demonstrate the intricate details involved in making healthcare decisions.

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I. AIM OF THE STUDY

The phenomenon of interest in this study is the issue of the informed choice process from the perspective of women who have modified or refused breast cancer therapies. This chapter begins with a justification for this focus that includes the specific context that surrounds women who have been diagnosed with breast cancer (also referred to as breast carcinoma) and who have participated in the process of deciding on their treatments. The decision to use a qualitative research method is explained and finally the relevance of this study to human ecology is discussed.

Phenomenon of Interest: Informed Choice Process

Statistically it is estimated that more than 175,000 new cases of female breast carcinoma will be diagnosed in the United States in 1999, and 43,900 persons will died of this disease; statistics are proportionately similar for Canada (approximately 93,000 new cases and 5,300 deaths) (Murphy, 2000). Breast cancer is the number one cancer site among women in North America, regardless of race/ethnicity, and it ranks second among all cancer deaths after lung carcinoma (Ries et al., 2000). The media report alarming sound bites such as "one-in-eight women will develop breast cancer in their lifetime" or "one woman dies of breast cancer every twelve minutes" (Rosenthal, 1999). When a woman receives a diagnosis of breast cancer, she has initiated the process of becoming informed regarding treatment options. The treatment decision impacts an extensive group of health care providers, the woman's family, workplace, and community.

The conventional medical procedures involved in a breast cancer diagnosis mark the beginning of the woman's involvement in the experience of breast cancer and the process of deciding what to do next. The woman's breast mass will have been diagnosed by self-examination, clinical breast examinations, mammography, ultrasonography and/or needle biopsies. Once the tumor has been diagnosed, the woman often deliberates over the causes of her breast cancer. Known risk factors for breast carcinoma include age at menarche and menopause, age at first childbirth, family history of cancer, levels of estrogen, cigarette and alcohol use, weight history, obesity, and body fat distribution at diagnosis (Kumar, Cantor, Allen, & Cox, 2000). Genetic changes occur during one's lifetime, and the longer one lives, the greater the chance that the cumulative effects of environmental toxins or radiation will result in genetic changes that will start the process of carcinogenesis (Haynes, 2000).

At the same time that a woman is searching for the origin of her cancer, she will most likely be required to select between surgical options: breast-conserving surgery or mastectomy. Moyer and Salovey (1998) stated that regardless of the choice of surgery, satisfaction with medical care depended on the woman's level of input into her treatment plan. Several weeks after surgery, when the biopsy of the breast carcinoma is completed, the woman will continue the consultation process concerning adjuvant therapies. The majority of women will accept their physicians' recommendations concerning chemotherapy and radiation (Lindley, Vasa, Sawyer, & Winer, 1998). This study will focus on the women who modified or refused the recommended adjuvant therapies. By

studying the process by which they reached this decision, greater insight into the internal and external factors that shaped their choice will be obtained.

The basic ethical premise for ensuring participation in the treatment decision making process is 'informed consent': the right to obtain complete, current information about diagnosis, proposed treatments, prognosis, risks and benefits of all treatment alternatives; and to receive information in terms the patient can understand (Beauchamp & Childress, 1994; Dunn, 1999). The client is included in deliberations concerning the complexity of treatment regimens, potential system toxicities, and the chronicity of the disease process (Varricchio & Jassak, 1989). The informed choice process is becoming more challenging as treatments become more complex and patients establish preferences for options that are outside the prescribed therapies (Adler, 1999; Swanson & Facione, 1998). Thus, an understanding of the processes used to make treatment decisions is both more difficult and more important than ever before.

Justification for Studying the Phenomenon

The majority of women with breast cancer agree to the chemotherapy and/or radiation therapy as prescribed by a multidisciplinary medical team. A preference assessment of breast cancer patients who underwent adjuvant cytotoxic and/or hormonal therapy estimated that more than 65% of patients were willing to undergo 6 months of chemotherapy for a 5% increase in likelihood of cancer cure (Lindley et al., 1998). Even women in later stages of breast cancer chose to undergo aggressive treatments such as peripheral stem cell transplants (National Cancer Institute, 2000). Approximately 34%, however, refused to accept adjuvant

therapy because it provided only a "small to modest" potential benefit, considering the possible risks. Siminoff and Fetting (1991) reported that, following surgery, women may experience a high level of frustration due to the minimal increase in survival rates resulting from chemotherapy and radiation therapy. Women may reject such treatment regimes, often referring to them as "slash, poison, and burn" (Zaloznik, 1994), because of their moral and cultural values, their work and social circumstances, and their responsibilities towards themselves and their families (Williamson, 1996).

The toxic side effects of adjuvant therapy are extensive and the following list is not exhaustive: premature menopause (Goodwin, Ennis, Pritchard, Trudeau, & Hood, 1999); cognitive impairment (Schagen et al., 1999); loss of sexual desire (Fallowfield, Leaity, Howell, Benson, & Cella, 1999); weight gain (Demark-Wahnefried, Rimer, & Winer, 1997); hair loss (Beisecker et al., 1997); and loss of childbearing capacity (Siegel, Gluhoski, & Gorey, 1999). Despite these side effects, studies indicated that the majority of women newly diagnosed with breast cancer preferred to leave treatment decision making to their doctor (Beaver et al., 1996). Investigators have proposed that the life-threatening nature of breast cancer reduced patient's cognitive abilities in terms of recall and retention of information, and compromised their ability to participate in the decision making process. An in-depth qualitative study by Pierce (1996) also indicated that most women facing treatment for early stage breast cancer will adopt a more simplistic decision strategy than one might expect or desire because they are involved in a serious and immediate threat to life.

However, in a large Canadian study by Degner et al. (1997), two thirds of the 1012 women preferred either active or collaborative decisional roles concerning their breast cancer treatment. Lack of appropriate information was the most striking reason that women felt uncomfortable with being active in the decision making process (Degner et al., 1997). When Guadagnoli and Ward (1998) reviewed the research both for and against patient participation in medical care, they found that the majority of patients want to be involved in treatment decisions when more than one effective alternative existed.

These findings lead one to wonder whether women comply because they did not have the ability to understand, lacked the information to participate in the decision making process, or did not perceive that they had the opportunity to participate in the decisions. There are very few studies concerning the decision making process for patients who refuse prescribed adjuvant therapies. Homedes and Ugalde (1994) identified reasons for "non-compliance" with treatment regimes: poor communication between practitioners and patients; poorly organized health services; cost of medicines; patient's feeling of improvement; and the nature of the treatment, such as side effects or lack of trust. Siminoff and Fetting (1991) determined that women who received more specific and a greater amount of information were more likely to reject their physician's primary recommendations. Treatment side effects and weakness in the physician's recommendations also caused women to reject the physician's counsel. Williamson (1996) found that health professionals and women who had already been treated for breast cancer were more likely to refuse to participate in trials.

Greater knowledge led potential participants to see some trials as methodologically or ethically flawed, however well they understood the trial's rationales.

These studies underscore the importance of conducting a study on treatment decision making that includes both women who have had a previous experience with cancer and those who have not. They also support the use of research methods that incorporate the context in which treatment decisions are made. This study will go beyond existing research concerning women who did not choose the primary recommended therapy for breast cancer. The human ecological approach allows the researcher to focus on the decision making processes that the women used and the context within which their decisions were made.

Qualitative Research Method

Both qualitative and quantitative research methods have been applied to the multidimensional aspects of the decision making process. In terms of quantitative analysis, the majority of the research on the informed choice process utilized Likert scales that call for standardized instruments to ensure generalizability, replicability and validity (Lynoe, Sandlund, & Jacobsson, 1996; Montgomery, Lydon, & Lloyd, 1999). However, these instruments typically contain generic questions that may provide limited insight regarding processes that have smaller sample sizes, like the one of interest in this study. The data from smaller qualitative studies may aid in the development of further quantitative research instruments.

Grounded theory, on the other hand, is a method that was developed explicitly for the discovery of processes. It promotes the identification of new theoretical relationships, rather than the confirmation of an existing hypothesis. Grounded theory allows the researcher to build the process as she goes, in accordance with the demands of the subject matter. The objective of continual re-evaluation of previous stages is to allow the emergence of relevant questions, with the objective being the discovery of general truths about human existence (Hamilton, 1989). Qualitative methods enable aspects of patient's lives to be raised that might otherwise go unheard, since they have an opportunity to speak in their own voice.

The objective of this study is to understand women's perception of the dynamic process of deciding to refuse adjuvant treatment. Since this process occurs within constantly changing circumstances, both internal and external, grounded theory is the qualitative method of choice (Chenitz & Swanson, 1986; Glaser, 1978; Glaser, 1992; Glaser & Strauss, 1967; Stern, 1980; Strauss & Corbin, 1997). The women will be invited to describe how and why they made their decisions: the experiential context within which they made their decision, and the research context that includes the personal and relational issues arising from their decision. An explanatory theory will be developed by using the hallmark techniques of grounded theory: theoretical conceptualization, constant comparisons (of causes, context, contingencies, consequences, covariances, and conditions) (Glaser, 1978), theory driven sampling, and memoing (Strauss &

Corbin, 1997). The outcome of the grounded theory method will be a theoretical explanation of the phenomenon of the refusal of adjuvant breast cancer therapy.

Relevance to Human Ecology

The human ecological view is appropriate for research concerning women's perception of the impact that their decision making process has on their relationships and their environment. Women with breast cancer are trying to make major life decisions that will affect them financially, emotionally, and socially. They are being asked to make a choice concerning invasive therapeutic regimes in the hopes of increasing their chances of survival. Illness demands are experienced in every aspect of these women's lives, including their identity, daily routines, family and social experience, and their perception of the past, present, and future. The human ecological framework provides a model that represents the interactions between the woman and the contexts within which she makes her decisions. The process that women go through as they make their decisions concerning breast cancer therapies reflects the social production of knowledge and behavior, within the cultures of biomedicine and family (Marshall, 1996).

What people *think* about the world will influence how they *act* in it. People's constructed realities are being negotiated on an ongoing basis. This study details in the women's own language the considerable influences that affect their decisions. The women remember past experiences of cancer in others and speculate on the causes of their breast cancer: radiation, pollution, food consumption patterns, personal habits, and/or genetic coding. Oncologists and oncology nurses provide decisional support that is experienced by the women as a

complex paradigm of choice involving multiple options and a variety of possible outcomes of substantial uncertainty (Carroll, 1998). Patients establish preferences for risks and benefits of treatment and seek further information from other health care providers, family, and community organizations. This study could illuminate ways of enhancing a cooperative informed consent process for patients, individuals in their support system, and health care providers.

II. EVOLUTION OF STUDY

Literature Review

Rationale

After the initial shock of being diagnosed with breast cancer, and the invasive surgery to remove the malignant tumor, the woman must choose whether or not to undergo further prescribed adjuvant therapies. Decisions concerning breast cancer treatment are complex and the ramifications of a woman's refusal of therapies are far reaching. This research will explore the intrapersonal and interpersonal influences on the breast cancer treatment decision. The human ecology framework provides a structure for exploring the internal and external environments within which treatment decisions are made.

The first section of the literature review describes the basis of the human ecology framework. The premise of this framework is that women make a decision within an environment that has internal and external components. The second section of the literature review describes the internal environment, which involves physiological and psychological factors that influence the decision making process (Gilligan, 1995). Physiological processes involve an understanding of the possible causes of breast cancer and an explanation of the methods of diagnosing breast cancer. The stages of breast cancer (see Table 1), estrogen receptor status (Table 3), and age of the women, are described because these factors impact treatment decisions and prognosis after the initial diagnosis and surgery. The explanations for the medical interventions that a woman with breast cancer will encounter are outlined in Appendix C: mastectomy, breast-

conserving surgery (lumpectomy), axillary node dissection, breast reconstruction, cytotoxic chemotherapy, endocrine therapy, radiation therapy, side effects of breast cancer therapies, and future directions in adjuvant breast cancer therapy. The final section on complementary and alternative medicine (CAM) provides an introduction to the additional options that are available to women with breast cancer. The psychological factors include decision making models, factors influencing decisions, quality of life issues, coping with decisions, and rejection of therapies.

The third section describes the external environment, which involves the influence of the relational and contextual factors that influence the women's decision process. Relational factors include family involvement in the process and contextual factors include social, cultural, and political issues that affect the process.

Human Ecological Framework

Human ecology deals with human beings in relationship to one another and to their surroundings. Maslow's (1939) concept of self-actualization and Roger's (1961) concept of fully-functioning people are incorporated into the human ecological model of efficient and effective interaction between individuals and their environments (Rogers, 1961; Westney, Brabble, & Edwards, 1988). The development of human beings is dependent on the human condition, and the composite of environmental circumstances, both internal and external. The internal environment, according to Gilligan (1995), includes the physiological processes of the body and the psychological aspects of an individual. Westney et

al.'s (1988) definition of the external environment encompasses the microenvironment and the macro-environment:

> The microenvironment includes the family, home, apparel, and interpersonal interactions between the individual and specific others. The macro-environment embraces the neighborhood, the community, the culture, the educational system, the church, the health care system, the economic system, government and the political system, social policies, as well as air, water, land, pollutants, environmental health conditions, occupational hazards. (p. 133)

The interaction of these human and environmental factors shapes the quality of life of people.

As a discipline, Bubolz and Sontag (1993) observe that human ecologists seek to enhance people's quality of life and well-being by exploring the connection between the behavior and health of people and the quality of their environment. They are interested in assessing how humans meet their goals, whether goals need to be changed, and what resources are lost and gained in the process. People establish control over their lives and environment by searching for the needed knowledge from many sources, together with a structure for that knowledge and its applications. Gilligan (1995) challenges researchers to go further and discover 'what is just' and 'how humans should respond'. Is the 'self' governing the action or does society shape the person and dictate the appropriate response?

Visvader (1986) acknowledges the role of human ecology in broadening research to include the multitude of stresses on individual, societal, and environmental health. The fundamental premise of human ecology, as stated by Westney et al. (1988), is to help human beings develop their capacity to manage their lives in a rational and effective manner. Humans develop an understanding of themselves in relation to the forces and counter-forces that impinge on their capacity to become fully functioning. The diagnosis of breast cancer alters a woman's social-psychological perspective and she has to adapt in order to maintain her life and interact with other systems. Nurturance activities, including household work and care of family members, may be difficult after surgery and during chemotherapy and radiation treatments.

Bubolz and Sontag (1993) emphasize that women may need to rely on their family and friends for support and assistance. Additional support systems, such as churches, 'Reach to Recovery' groups, and the Internet, may provide knowledge to assist in the decision making process, and increase the woman's capacity for adaptation and survival (Bubolz & Sontag, 1993). Several studies mention the familiar web of interdependence of the economic, nurturance and socialization functions that existed within a person's family and community (Bubolz & Sontag, 1993; McIntosh, 1985). A diagnosis of breast cancer alters the woman's perspective of her once familiar web of interdependence.

The informed choice process requires a person to make a decision concerning treatment that may bring his/her body and life back into a state that is ordered and organized. However, the fact that a person has made a decision does

not mean that the issue has reached resolution and closure. Quality of life is subjective and the personal, relational and contextual factors that influence this measurement are numerous and overlapping. This study explores the responses of women who have made a decision about their breast cancer treatments amidst all the influences from their unique internal and external environments.

Internal Environment

Physiological Factors

While researchers will admit that there is no definitive answer to the question "Who gets breast cancer, and why?", there is considerable evidence that breast cancer risk is linked to genetics, lifestyle, and environment (Rosenthal, 1999). Women with breast cancer face the possibility that their family shares a susceptibility gene that may increase their risk of early onset lung and breast cancer (Schwartz, Siegfried, & Weiss, 1999). However, Curry and Fentiman (1999) indicated that genes are thought to be responsible for only 5% to 10% of breast cancer cases. The level of female hormone, estrogen, is also linked to the risk of developing breast cancer (Chlebowski & McTiernan, 1999). Increased estrogen may be the result of genetics, lifestyle, or environment: early menses, late menopause, having their first child later in life, consuming estrogen orally, having increased levels of hypertension, or having a predominant central body fat distribution (android) (Armstrong, Eisen, & Weber, 2000; Kumar et al., 2000; Soler et al., 1999). Women with breast cancer must decide among treatment options that include conventional therapies that act on the localized and systemic effects of breast cancer. They may also consider alternative therapies that attempt

to halt the development of breast cancer by modifying the internal and external conditions that trigger the defective gene and stimulate excessive estrogen production, or by boosting the immune system (Sherwin, 1996).

Diagnosis of Breast Cancer

Primary treatment decisions are based on the type, size, and histology of the tumor as well its location in the breast and lymph node involvement (Winchester, 2000). The accuracy of initial diagnosis of breast cancer is 70% to 90% by physical examination, 85% to 90% by mammography, and 90% to 99% by fine-needle biopsy (Roses, 1999). Ultrasonography is used to differentiate cystic from solid masses and to distinguish benign from malignant tumors; an ultrasound-guided needle biopsy is used to obtain a reliable tissue diagnosis and thereby to reduce the number of unnecessary open surgical biopsies (Singletary & Robb, 2000).

Statistically, only 18% of women who are left untreated (i.e. refusal of surgery and all therapies) will be alive in 5 years and only 4% will be alive in 10 years with no treatment (Harris, Hellman, & Kinne, 1987). Refusal of surgery is very uncommon, so studies have focused on the decision making process from the perspective of choosing between having a mastectomy or breast conserving surgery plus postoperative radiation therapy (Keller, 1998; Moyer & Salovey, 1998; Stafford, Szczys, Becker, Anderson, & Bushfield, 1998; Street & Voigt, 1997; Weiss, Wengert, Martinez, Sewall, & Kopp, 1996). Surgical removal of the tumor after preliminary biopsy (see mastectomy and lumpectomy in Appendix C), confirms the clinical or radiological suspicion of malignancy (Roses, 1999).

Axillary lymph node involvement is an important predictor of systemic disease (Barse & Masny, 1998) (see axillary node dissection in Appendix C).

Staging of Breast Cancer

Once a diagnosis of breast cancer has been established, the staging of the disease provides the basis for the selection of the appropriate treatment to manage both the local disease within the breast and the potential/existing metastasis (Denton, 1995). The current clinical and pathological TNM (primary tumor [T], regional nodes [N], and distant metastasis [M]) staging system outlined by the American Joint Committee on Cancer (1992) requires an examination of the breast, the skin on the breast, axillary lymph nodes, and the chest wall to determine staging (Table 1). Lesions that are 2 cm or less are staged as T1 lesions. The T1 lesions have been further subdivided to predict prognosis. Any cancer less than 0.5 cm is a T1a lesion, while those between 0.5 and 1.0 cm are T1b, and all lesions greater that 1 cm up to 2 cm are considered T1c tumors. Stage T2 includes all tumors between 2 and 5 cm. T3 tumors are those that exceed 5 cm in greater dimension. T4 lesions are staged according to local extension. Tumors extending to the chest wall are T4a, while those involving the skin with ulceration or edema are staged as T4b. If tumors fulfill both criteria for T4a and T4b, they are T4c lesions. Inflammatory cancers are staged as T4d (Roses, 1999).

The stage I, II, III, IV system (Table 2) provides an approximate idea of the extent of disease by combining the TNM information to assist in the development of a treatment strategy. Stage 1 represents early cancer, with a small tumor and no spread to the lymph nodes in the armpit. In stages II and III, the

tumor is progressively more advanced, while stage IV refers to metastatic disease that has spread to other areas of the body (Olivotto, Gelmon, & Kuusk, 1996).

Table 1. The American Joint Committee on Breast Cancer Staging System

Primary Tumor (T)		
TX	Primary tumor cannot be assessed	
T0	No evidence of primary tumor	
TI	Carcinoma in situ	
T1	Tumor ≤ 2 cm in greatest dimension	
	T1a	< 0.5 cm
	T1b	> 0.5 – 1.0 cm
	T1c	1-2 cm
T2	Tumor > 2-5 cm in greatest dimension	
T3	Tumor > 5 cm in greatest dimension	
T4	Tumor of any size with direct extension to the chest wall or skin	
	T4a	Extension to the chest wall
	T4b	Edema of the breast skin, ulceration of the skin, or satellite skin nodules
	T4c	Both T4a and T4b
	T4d	Inflammatory carcinoma
Regional Nodes (N)		
NX	Nodal status cannot be assessed	
N0	No regional nodal involvement	
N1	Metastasis to mobile lymph nodes in the armpit only	
N2	Metastasis to lymph nodes in the axilla are fixed to one another or other structures such as nerves, muscles, skin or bones	
N3	Metastasis to lymph nodes beside the breast bone	
Distant Metastisis (M)		
MX	Distant metastasis cannot be assessed	
M0	No distant metastasis	
M1	Distant metastasis including spread to lymph nodes above the collarbone	

Early stage of breast cancer includes ductal carcinomas in situ (DCIS) as well as invasive tumors in stage I-II (Table 2). Ductal carcinoma in situ (DCIS/intraductal carcinoma/noninvasive ductal carcinoma) is a proliferation of

malignant cells confined within the basement membrane of the ducts of the breast (Schwartz, Solin, Olivotto, Ernster, & Pressman, 2000). These stage I-II tumors are generally between 0 and 5 centimeters in size, with a spread limited to the axillary lymph nodes, or without lymph node involvement (Singletary & Robb, 2000).

Table 2: Combination of the TMN Staging of Breast Cancer

Stage	Criteria	Average 5-yr survival
Stage 0	Non-invasive carcinoma: ductal carcinoma in situ or lobular carcinoma in situ or Paget's Disease of the nipple with no underlying tumor, and no cancer in the lymph nodes or metastases in distant parts of the body.	
Stage I	Tumors ≤ 2 cm with negative lymph nodes and no metastases in distant parts of the body.	80% to 95%
Stage IIA	Primary tumor cannot be found but movable positive lymph nodes or tumor ≤ 2 cm with movable positive lymph nodes or tumor 2-5 cm with negative lymph nodes and no metastases in distant parts of the body.	50% to 70%
Stage IIB	Tumor 2-5 cm with movable positive lymph nodes or tumor > 5 cm with negative lymph nodes and no metastases in distant parts of the body.	
Stage IIIA	Primary tumor cannot be found but fixed lymph nodes or tumor ≥ 5 cm with movable or fixed lymph nodes and no metastases in distant parts of the body.	30% to 60%
Stage IIIB	Tumors of any size with these features: extension to chest wall, dimpling of skin, skin ulceration, satellite nodules, edema, inflammatory cancer or any size tumor with metastatic involvement of the internal mammary lymph nodes and no metastases in distant parts of the body.	
Stage IV	Any size tumor with any lymph node involvement with distant metastases.	5% to 20%
	(Barse & Masny, 1998; Olivotto et al., 1996)	

A significant proportion of patients with stage I, II, or III disease (see Table 2) will be treated with chemotherapy and/or endocrine therapy (e.g., tamoxifen) (Kumar et al., 2000), as well as loco-regional radiotherapy (Roses, 1999). The widely held belief that all breast cancer is a systemic disease coheres with the current emphasis on the importance of systemic therapies for disease control and cure (Singletary & Robb, 2000). The growing recognition that some early disease is localized, however, has resurrected the importance of controlling local disease and through the use of radiotherapy (Levitt & Kennedy, 1998).

The survival expectancies in Table 2 are quite variable because of the broad range of disease in each stage. The five-year survival rates are only estimates and the individual survival rates may be quite different (Olivotto et al., 1996). The following conventional therapies are discussed in more detail in Appendix C: mastectomy, breast conservation with lumpectomy and radiation therapy, axillary node dissection, breast reconstruction, cytotoxic chemotherapy and endocrine therapy and the accompanying side effects, radiation therapy, and the future direction of cancer therapies.

Adjuvant Treatment Decisions

Adjuvant treatment decisions are based on calculating the individual's risk of recurrence and applying the possible benefit of chemotherapy and/or endocrine therapy by considering numerous factors: the staging of the disease, menopausal status, tumor steroid-receptor status, a person's age, and general health (Singletary, 1998; Veno-Sharp & Mrozek-Orlowski, 1998). The National Cancer Institute advocated for the standard use of chemotherapy for premenopausal node-

positive patients and a change in the perception of the disease itself from one that was sometimes localized to one that was systemic (cited inLevitt & Kennedy, 1998). Still questioned, however, is whether women with negative nodes and lesions of 1 cm or less benefit from adjuvant chemotherapy (Schwartz et al., 2000).

A 1995 consensus panel determined that tamoxifen was the preferred adjuvant treatment for all estrogen receptor-positive, node-positive, postmenopausal patients and all elderly patients (Table 3). Tamoxifen is now used in postmenopausal patients where the lesions are greater than 1 cm (stage 1) (Levitt & Kennedy, 1998).

Induction chemotherapy (preoperative chemotherapy) is now used for subgroups of patients with large tumors (greater than 5 cm), based on the idea developed earlier in hormonal studies that reducing tumor size prior to surgery predicted increased survival rates (Levitt & Kennedy, 1998). Survival improved in women with tumors greater than 5 cm given preoperative chemotherapy followed by lumpectomy and radiation.

Continuing development of chemotherapy combinations involving new agents (e.g., taxanes, bisphosphonates, tamoxifen analogs) will add to the complexities of the best sequential use of the three major treatment modalities (Levitt & Kennedy, 1998). (See Appendix C for new approaches in drug therapy not identified in Table 3.)

In addition to decisions about surgery and systemic treatment, women who choose mastectomy (or for whom lumpectomy is not an option) may also opt for

reconstructive surgery. Therefore, an explanation of these surgical options is included in Appendix C.

Table 3: Adjuvant Therapies -1995 International Consensus Panel

Breast Cancer Classification	Adjuvant Therapy Recommendations	
	Primary	Supplemental[3]
Node-Negative		
T < 1cm, Estrogen Receptor (ER) positive, grade 1, age > 35 years	None	Tamoxifen
T 1-2 cm, ER-positive, grade 1-2	Tamoxifen	Chemotherapy
T > 2 cm and/or grades 2-3		
Premenopausal ER-positive	Chemotherapy	Tamoxifen
Premenopausal ER-negative	Chemotherapy	None
Post-menopausal ER-positive	Tamoxifen	Chemotherapy
Post-menopausal ER-negative	Chemotherapy	Tamoxifen
Node-Positive		
Premenopausal ER-positive	Chemotherapy[4] Ovarian ablation	Tamoxifen Tamoxifen
Premenopausal ER-negative	Chemotherapy	None
Post-menopausal ER-positive[1]	Tamoxifen	Chemotherapy
Post-menopausal ER-negative	Chemotherapy [2]	Tamoxifen
[1]Note: Tamoxifen is the treatment of choice. However, some studies now demonstrate an additional benefit from chemotherapy in this population. Chemohormonal therapy should be discussed as an option. This option may be precluded by the patient's age and physical health (Veno-Sharp & Mrozek-Orlowski, 1998).		
[2] Note: Chemotherapy is the treatment of choice, although some argue that tamoxifen may also be beneficial despite negative receptors (Veno-Sharp & Mrozek-Orlowski, 1998).		
T: Tumor size; ER: Estrogen receptor [3] Note: Not in routine use		
[4] Note: T>4cm: Consider high dose therapy (Reed, 1996)		
National Comprehensive Cancer Network (NCCN) Breast Cancer Guidelines, 2000 (Ades et al., 2000; Singletary, 1998)		

While the medical protocol defines the treatment for each stage of cancer, each woman is an individual and the stages of breast cancer do not reflect the

psychological aspects of adjustment that affect the decision making process for women with breast cancer. Frost et al. (2000) found that individuals with recurrent disease experienced more difficulties with physical, psychological and social well-being than women in the other groups (newly diagnosed, adjuvant therapy, and stable disease). Their difficulties living day to day and functioning socially may have an effect on their perceptions of additional therapies that have accompanying side effects. The newly diagnosed group experienced more difficulty with pain than the other groups, while women in the newly diagnosed group and in the adjuvant group experienced more role limitations as a result of emotional problems. Women who were newly diagnosed, and those with adjuvant or recurrent diseases, all required assistance in decreasing role demands during the early phases of their disease process (Frost et al.). These individual differences are as varied as the women who present with breast cancer, and these variations will not all fit into one neat little table.

Age of Women Diagnosed With Breast Cancer

Age is a very strong determinant of breast carcinoma treatment. Women who are 50 years of age have double the risk of women who are 40 years of age, and the risk doubles again by the age of 70 (Olivotto et al., 1996). Currently, nearly 50% of the new cases and nearly two-thirds of the deaths from this disease occur among the 13% of women aged 65 years or older (Mandelblatt et al., 2000). Mandelblatt, et al. (1992) clearly demonstrated that the majority of women older than 65 years had not been adequately screened for breast cancer. Along with advancing age, there are increases in comorbid medical problems, and the issue

then becomes a balance between the treatment of the cancer and the overall life expectancy and quality of life of each woman (Singletary & Robb, 2000).

Table 4: 10 Year Survival Estimates by Age, Risk of Breast Cancer Death, Adjuvant Therapy

Risk of Breast Cancer Death	Natural Morbidity	No Adjuvant Therapy	Adjuvant Therapy	Absolute Benefit	Recommend-ation
40 years old					
Low 10%		88%	90%	2%	no treatment
Interm 28%	2%	71%	77%	6%	(+/-)CMForAC
High 57%		41%	51%	10%	CMF or AC
65 years old					
Low 9%		73%	75%	2%	no treatment
Interm 26%	19%	58%	63%	5%	TAM (ER+)/CMF/0
High 54%		34%	43%	9%	TAM (ER+)/CMF
cited in: (Harris & et al., 2000)					

Postmenopausal Women

Some clinicians consider modest reductions in quality of life to be a reasonable consequence of treatments for 50-year-old postmenopausal women if increased survival is likely.

> Among 50-year-old postmenopausal women with node-positive, receptor-positive disease, approximately 500 of 1,000 patients observed for 10 years will die of breast cancer. Tamoxifen will reduce this risk by approximately 25% and result in 125 fewer breast cancer deaths. Against this substantial benefit, the mortality associated with the side effect, endometrial carcinoma, is about one per 1,000 patients treated with

tamoxifen, and this is considered to be an acceptable medical risk" (Chleboski & McTiernan, 1999, p. 136). [see Appendix C for side effects of endocrine therapy]

There are significant differences in the treatment regimens for women over 70 years of age. Results from a study by Hebert-Croteau, Brisson, Letreille, Blanchette, and Deschenes (1999) revealed that women age ≥ 70 years were much less likely to receive radiation therapy, dissection of the axillary nodes, or chemotherapy, in comparison with women ages 50-69 years. Lymph node dissection was considered to have doubtful therapeutic value. Patients with higher comorbidity were less likely to receive therapeutic modalities. Investigators who studied patterns of breast carcinoma treatment in older women, reported that women 80 years and older were 3.4 times more likely to have radiotherapy omitted after a lumpectomy than women ages 67-79 years, independent of comorbid illnesses, physical functioning, or women's treatment preferences (Mandelblatt et al., 2000). Postmenopausal women treated with lumpectomy plus radiation had a statistically significant reduction in local recurrence compared with patients treated by lumpectomy alone (10% vs. 35%, $P < .011$) (Roses, 1999). Women 80 years and older were also receiving chemotherapy 70% less often than women 67-79 years with similar tumor characteristics and health (Mandelblatt et al., 2000).

Women age > 50 years were more likely to have received tamoxifen than the younger age group and they are more likely to have estrogen-receptor positive tumors (Hebert-Croteau, Brisson, Latreille, Blanchette, & Deschenes, 1999;

Wenzel et al., 1999). However, Chung, Chang, Bland, and Wanebo (1996), found that only about one-half of women over the age of 80 years received adjuvant tamoxifen. Physicians appear to offer less aggressive therapeutic alternatives to patients, arguing that they are less able to tolerate the side effects and the subsequent reduction in quality of life, despite the potential improvement in survival (Hebert-Croteau et al., 1999).

Women aged 53 years and older were more comfortable making treatment choices themselves than women age 52 and under, and were less likely to have specific fears concerning breast cancer (Johnson et al., 1996). Previous studies show that older individuals have dealt with more life crises and therefore are better equipped to cope with breast cancer than women age < 50 years (Mor, Aleen, & Malin, 1994). The older women appear relatively unwilling to accept 6 months of chemotherapy for any identifiable improvement in clinical outcome (Lindley et al., 1998).

Utley (1999) found that as older women who are long-term survivors of breast cancer worked through their cancer experience (lumpectomy and radiation or mastectomy with/without chemotherapy), their perspectives changed: from cancer as sickness and death, to cancer as an obstacle, and finally to cancer as transforming. The conclusion was that women's perspectives after surviving breast cancer and its treatment, centered around positive, insightful experiences and expansive, renewing interactions with their environments (Utley). Clinicians think that a decrease in the quality of life is acceptable for women around 50 years, but not for women in the 70+ category. However, the women in the 50 year

age group also value quality of life and are not necessarily willing to tolerate a reduction in the quality of life for an increased chance of survival, particularly when the increase in life expectancy is small.

Premenopausal Women

Women of age ≤ 50 years were more likely to have received chemotherapy, and they were more likely to have received treatment of any type lasting three months or longer, than women of age > 50 years with similar disease characteristics (Wenzel et al., 1999). However, younger women reported greater difficulty tolerating chemotherapy, maintaining their daily routine, and greater mood disturbance than older women (Wenzel et al., 1999) (Cimprich, 1999). These findings are not surprising, given the reports, outlined above, showing that they are given more aggressive treatments. It has been noted in general that younger women are considered less able to cope with treatment-related side effects [see Appendix C], to accept a diagnosis of cancer, to maintain a positive attitude, to regulate their affect, and to seek support (Wenzel et al., 1999).

Adverse economic consequences of breast carcinoma were more likely for younger patients than for older patients (Nugent, 1995). Breast carcinoma has the potential to be devastating to the sexual function and self-esteem of premenopausal women, noting that women who have received chemotherapy are especially susceptible to adverse changes in their current sexual functioning compared with those treated with hormonal therapy and radiation therapy (Young-McCaughan, 1996). Dunn and Steginga (2000) reported that young women feel isolated and different from their pre-existing peer groups. These

young women were upset that the media emphasized the early and tragic death and featured bereaved families (Clarke, 1999). Concerns about not surviving to see their children grow to adulthood, and about infertility, lead to anxiety, depression, fear and anger (Dunn & Steginga, 2000).

Since the disease has altered the future of the young women with breast carcinoma and caused them emotional distress and financial hardship, it is interesting that they will accept even a minimal increase in survival (see Table 4) regardless of the side effects of intensive chemotherapy (a median improvement in cure of 2%) ((Lindley et al., 1998). Johnson et al. (1996) reported that women age 52 years and under were more likely to want their doctors to make a recommendation, and suggested that physicians encourage these women to discuss their fears concerning breast cancer.

Alternative/Complementary Medicine

The following definition of complementary and alternative medicine was developed in 1997 by the National Center for Complementary and Alternative Medicine in the United States:

> Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well being. Boundaries within CAM and between

> the CAM domain and the domain of the dominant system are not always sharp or fixed. (cited inAdler, 1999, p. 215)

When women turn to dietary changes, herbs, vitamin supplements, exercise, visualization, meditation, and immune-system-stimulating products in their health care programs, they may use them to back up a conventional treatment program (complementary medicine), or they may use the same therapies as alternatives (Wooddell & Hess, 1998).

Studies indicate that people with cancer who seek complementary/ alternative medicine (CAM) are striving to regain or maintain a sense of control over their lifestyles and health (Fryback & Reinert, 1997), and they are deeply engaged in fighting for recovery (Lerner, 1994). Swanson and Facione (1998) identified activities demonstrated by women with breast cancer who choose CAM: active participation in healthcare decisions, familiarity with the lay press and popular literature, access to CAM practitioners, and attendance at breast cancer support groups. The users of alternative medicine are more likely to be well-off, better-educated (Montbriand, 1994), and young adults (Blais, Maiga, & Aboubacar, 1997). The utilization of alternative health care practitioners by Canadians and Americans in Millar's (1997) study was significantly higher among women, the more educated, higher income groups and in the Western provinces and states.

Cancer patients may be influenced by a social group endorsing a specific CAM practice, anger at the medical system, fear, or the economic burdens of conventional treatment (Montbriand, 1994). Another possible factor in seeking

CAM comes from a sense of isolation and antiestablishment feelings toward organized medicine (American Cancer Society, 1999). Holland (1999) hypothesized that users of alternative medicine may be more knowledgeable about the enormity of breast cancer, and so more susceptible to anxiety and depression.

The Burton Goldberg Group, a team of over 350 medical doctors, naturopaths, osteopaths, homeopaths, chiropractors, acupuncturists, scientists, researchers and reporters have compiled forty-two general alternative therapies, and 12 specifically used for cancer. They quote the Chinese saying about "the wisdom of 'walking on both feet', which means using the best of European and Western procedures" (The Burton Goldberg Group, 1995, p. XXXVII). However, they caution that the information is meant solely as a first step in the education process concerning cancer and the factors involved in treatment (The Burton Goldberg Group, 1995). Readers are advised not to undertake the methods without medical supervision.

Alternative therapies seek to strengthen the immune system of the cancer patient, and generally shun the use of highly toxic modalities, such as radiation and chemotherapy. Instead, they prefer to heal the entire body, and employ what they claim is a multifaceted, nontoxic approach, incorporating treatments that rely on nontoxic methods: biopharmaceutical, metabolic therapies, and mind-body interventions (The Burton Goldberg Group, 1995). Biopharmaceutical therapies include the use of antineoplaston therapy, 714X (a solution of nitrogen-rich camphor, developed by the Quebec biologist Gaston Naessens), hydrazine sulfate,

shark cartilage, vitamin C therapy, and laetrile (National Cancer Institute, 2000). Each of these therapies has in common the use of nontoxic, naturally-derived compounds that rebalance the body's biochemical functioning (The Burton Goldberg Group, 1995). Metabolic treatments include an eclectic mix of diet and nutritional supplementation, herbal medicine, detoxification, immune stimulation, and enzyme therapy (Wooddell & Hess, 1998). The therapeutic goal of such therapies is to rebuild and revitalize all of the body's life-sustaining functions, thereby eliminating all traces of disease (The Burton Goldberg Group, 1995).

Some examples of mind-body interventions are psychotherapy, hypnosis, stress management, visualization, yoga, Qi Gong, meditation, chanting, therapeutic touch, reflexology, reiki, and aroma therapy. Acupuncture has been studied as a complementary therapy by the National Institutes of Health Office of Complementary and Alternative Medicine: they reported that the incidence of postoperative and chemotherapy nausea and emesis could be reduced with acupuncture therapy (National Institutes of Health Consensus Conference, 1998). Stress relief, relaxation and a sense of gaining control over one's body, are some of the benefit of these therapies.

Opponents of CAM

Crone and Wide (1998)reported the risks of herbal remedies that result from the ignorance of patients and physicians. Such products are neither placebos, benign, or without therapeutic worth. Their advice is that physicians and patients should be aware of the potential side effects, toxic reactions, and unwanted herb/drug interactions. Hirshaut's and Pressman (1996) consider reliance on

alternative treatments to be "a prescription for tragedy"(p. 93) and "*not* a substitute for good medical treatment" (p. 94).

Zucker (1996) reported that decisions concerning alternative health care must be rooted in a foundation of beliefs with respect to healing and the body, or the information will be virtually useless. Since a person's body has to do the healing, health care providers are seen as partners, not authority figures, which may be the appeal of CAM (Knobf & Pasacreta, 1999). However, Zucker emphasizes that the information on CAM is extensive and the task of choosing among them may add to the complexity of the decision making process. Wooddell and Hess (1998) caution patients that the sense of control over treatment options is not guaranteed with the switch to alternatives; patients need to be just as vigilant when alternative practitioners offer a 'cure' for cancer. As with conventional therapies that fail, relying on alternative medicine to restore one's health may result in distressing disillusionment if the results are not positive (Holland, 1999).

Summary

The physiological factors within the women's internal environment included a description of the current breast cancer diagnoses and treatment protocols, and what is known about the women's most frequent treatment choices. Research concerning medical protocols demonstrates how the physician's perceptions concerning the patient's age and co-morbidities may influence the physician's decisions concerning the prescription of therapies. The range and application of alternative therapies was addressed because the women who

modify or refuse prescribed therapies may turn to CAM to supplement or replace prescribed therapies.

Psychological Factors

This part of the literature review will examine decision making theories, dimensions that women consider when deciding quality of life concerns, coping patterns of women who have chosen between alternative therapies, and the refusal of the physician's primary treatment.

Decision Making Theories

In the mid-1970s, behavioral research on the decision making process began to focus on information processing as it relates to social behavior (Siminoff & Fetting, 1991). Janis and Mann (1977) moved beyond normative models of prescribing what people 'ought ' to do in a given situation and developed a decision making model that examined real-life choices that affect individuals. Janis et al. developed seven criteria for making a quality decision: (1) accepts a realistic challenge involving alternatives; (2) actively searches for and views a number of alternatives; (3) considers advantages and disadvantages of each alternative; (4) searches out new information; (5) assimilates new information correctly even if it does not support the preferred choice; (6) reviews consequences of all alternatives; and (7) thoughtfully sets out to implement the chosen alternative but remains aware that contingency plans may be necessary. Several studies have used this model as a basis for determining the quality of the decision making by women with breast cancer (Pierce, 1993; Reaby, 1998).

Pierce (1993) modified Janis' and Mann's model in order to describe the decision making process of women newly diagnosed with early breast cancer that were choosing between mastectomy and breast conserving surgery. Pierce used grounded theory to identify five indicators of decision behavior: (1) perceived salience of alternatives; (2) decision conflict; (3) information seeking; (4) risk awareness; and (5) deliberation. Pierce (1993) condensed the five decision behaviors to reflect three decision styles prevalent among women with breast cancer: deferrer, delayer, and deliberator. The "deferrer" group (41%) frequently attributed their decision to the physician, to God, or to fate. They reported an uncomplicated, rapid, and apparently intuitive decision making experience, with little distress and higher degree of satisfaction than the other groups. Janis and Mann (1977) referred to this deferring behavior as *unconflicted adherence*. The "delayer" group (44%) appeared to vacillate between at least two options. These women would make a decision when they perceived the first detectable difference between the two available options that allowed them to them to make a choice. They required more time and experienced more distress. As their concern about the quality of their decision increased, their satisfaction with their decision decreased and they became more distressed. The "deliberator" group (15%) reported a deliberate, purposeful process for gathering information, making a decision only after all relevant information was considered. Despite their deliberative process, they were less confident about their decision, and used more resources of time, expert opinion, and information (Pierce).

Reaby (1998) also used Janis' and Mann's (1977) decision making model to study women who had chosen a mastectomy. Reaby identified three predominant coping patterns: (1) satisficing, (2) complacency, and (3) defensive avoidance. Satisficing refers to the acceptance of information, without actively searching for an optimum solution, after a minimal level of required information was given. Complacency refers to the acceptance of advice without questions or full comprehension: the person does not investigate alternatives and simply hopes for the best. Defensive avoidance refers to the vacillation between choices and the reinterpretation and rationalization of advice and knowledge. Defensive avoidance also refers to the avoidance of discussion and denial of the problem. Reaby acknowledged that there were no participants in the study who fit Janis et al.'s criteria for making a quality decision: actively searching for information; considering the positive and negative aspects, and freely discussing the choices with family and friends. However, Reaby also acknowledged that the study did not interview women who chose not to have a mastectomy.

Quality of Life

The stress created by a diagnosis of breast cancer, the possibility of death, the technical difficulty of the treatment information and the perceived urgency of the situation make it difficult for women to seek out information. This state of emotional turmoil may contribute to the rapid decision observed in the majority of the patients. They may have arrived at their decision on the basis of intuitive factors such as fear, hope and (anticipated) decision regret.

Several studies have focused on the level of satisfaction women experience with their decision concerning their chosen surgery. According to Ashcroft, Leinster & Slade (1985), the five dimensions that women consider when deciding 'quality of life' concerns in regards to breast cancer are: (1) recurrence; (2) attractiveness and self-evaluation; (3) side effects of therapies; (4) the reaction of significant others; and (5) social support for each option. Moyer and Salovey (1998) examined the extent to which patient participation in the choice of surgical options was related to psychological functioning, fear of cancer recurrence, and aspects of treatment satisfaction 3 and 13 months postoperatively. They found that women who had higher levels of participation in their treatment plan were more satisfied with their medical care a year after surgery, although they were not better off in terms of psychological functioning or fear of cancer recurrence (Moyer & Salovey, 1998). A significant percentage of mastectomy patients in Weiss et al.'s (1996) study thought they had made the appropriate choice of therapy, even though the results were more disfiguring than anticipated. The women were confident that their chosen treatment provided the best chance for cure, even though they were informed that the long term prognosis was the same for either surgery (Weiss et al., 1996).

Street and Voigt (1997) attended the consultations between women and their surgeons. They found that when the patients believed they were more responsible for treatment decisions and that they had more choice of treatment, they reported higher levels of quality of life than did the patients who perceived themselves to have less decision control (Street & Voigt, 1997). The main goal of

the women in Kraus's (1999) study was survival. When faced with a life-threatening situation, the women in Kraus's study who believed that they were active participants in the treatment decision, and had a treatment choice, experienced a positive adjustment to their breast cancer surgical treatment. However, Fallowfield (1997) found that providing information and choice of surgery to women does not prevent psychological distress (fear of cancer recurrence).

Pierce (1993) hypothesized that women exclude options they would prefer because they are too overwhelmed to effectively overcome barriers. Since stress interferes with cognitive assimilation of vital information concerning treatment choices, and the process of obtaining a second opinion is daunting (Reaby, 1998), it is not surprising the increased physician certainty regarding diagnostic and treatment behavior is associated with increased reliance on the physician to make the 'correct' decision (McKinlay et al., 1997).

Huizinga, Slwijfer, van de Wiel, and van der Graff (1999) insights revealed that patients decide about participation in phase III cancer clinical trials "instantaneously" (only 1 patient in 14 refused to be in the trials). The 13 patients all mentioned the following reasons for participating in the trials: "the desire to get well, the hope for a cure or prolongation of life, and the opportunity to help other future patients" (p. 123). Huizinga et al.'s concern over the rapidity of the decision process prompted them to suggest a list of strategies to support the patient in making a well-considered decision: (a) information aids that assist patients in accessing information (e.g. providing relevant Internet addresses); (b)

videotape decision aids that encourage patients to participate with their physician in medical decisions; and (c) psychological aids that encourage the patient to define his or her personal values concerning participation in a clinical trial and searching for alternatives (Huizinga et al., 1999).

Coping with their Decision

Decision making parameters may be important determinants of post-treatment adjustment. Several studies indicate that a woman's perception that she can make an autonomous decision may be more important than the treatment itself in influencing adjustment (Meredith et al., 1996; Morris & Royle, 1988). Women who demonstrated low avoidance in their coping strategies were significantly better adjusted and less distressed than women who avoided active involvement in treatment decision making concerning their breast cancer treatment (Hack & Degner, 1999).

In a study concerning various cancer-related screening and management regimens, Miller (1995) addressed the need to tailor information to the individual's coping style by identifying two main psychological coping styles:

> The first mode, *monitoring* (attention to scanning for, and amplification of threatening cures), involves the extent to which individuals are alert for and sensitized to the negative, potentially painful, or dangerous aspects of information and experience. The second mode, *blunting* (avoidance of threatening cues), involves the extent to which individuals distract themselves from such information. (p. 168)

While the high monitors seek voluminous preparatory information to work through their cancer experience, they generally defer to a more competent individual. However, Miller found that high levels of monitoring may produce anxiety when, for example, an individual learns that she is at high genetic risk for breast cancer and she believes that the situation is intensely threatening and uncontrollable. In this context the woman may require emotional support to deal with the information and accommodate to her medical situation. Blunters in this same situation would decide immediately not to look for threat-relevant information and potential threats because it interferes with self-distraction and they prefer to downplay the event. Millar's suggestion is to match the amount of information and level of support to the patient's coping style (i.e. giving monitors more and blunters less), in order to reduce their level of stress.

Shapiro et al. (1997) stated that a critical component in optimal coping may be a willingness to discuss and think about illness. All the women in their study had surgical interventions for stage II breast cancer. Shapiro et al. established four coping patterns for differences in physical and psychological side effects during treatment with adjuvant chemotherapy: (1) confrontive, (2) avoidant-confrontive, (3) avoidant-resigned, and (4) resigned. As a consequence of being more willing to discuss and think about illness, confronters were significantly better physically and psychologically than avoidant-confrontive copers who chose to distract themselves and avoid discussing their cancer with family and friends. However, the researchers did acknowledge that they did not

control for the participants' psychological and physiological state prior to adjuvant chemotherapy.

Stanton et al. (1998) studied women with breast cancer who perceived that they had less choice over their surgical decision. The more they perceived that the outcomes violated their original expectancies about procedure benefits, the greater was the likelihood of adjustment difficulty over time. One year after diagnosis, women were less likely to believe that treatment would prevent recurrence than before their surgery. This is despite the fact that no women actually had experienced recurrence and highlights the importance of concerns about recurrence in the quality of life of cancer patients (Stanton et al.). All the women in Stanton et al.'s study rated their partners as extremely supportive of their decision, and their physicians were also in total agreement with the decisions. However, all of the women chose between the selection of options presented to them; they did not refuse all of the options. No studies have examined if the physicians and spouses when women refuse all adjuvant therapies offered.

Modification and Refusal of Therapies

Approximately six weeks after the initial surgery (mastectomy or lumpectomy) the women with stage I - stage IV cancer will likely be given the option of chemotherapy, an intervention that provides an absolute benefit of 10% or less (Table 4). Monson and Harwood (1998) determined that 70% of women with early stage breast cancer will be cured by local surgical treatment alone. In Siminoff and Fetting's (1991) study, 80% of the patients were strongly influenced by the physician's recommendation; 20% of the patients chose to disregard their

physician's recommendation concerning adjuvant therapy. Siminoff and Fetting (1991) examined the decision making process of this small minority of women with breast cancer who rejected their physicians' primary treatment recommendations. Their study revealed that patients with higher levels of education and patients who have more specific understanding of the benefits of adjuvant therapy were less likely to accept their physicians' primary treatment recommendations. However, only 3% of those patients actually chose not to take *any* of the possible recommended treatments. Rather, the 17% who did not chose the primary treatment recommendation were divided between taking less risky treatment (in terms of side effects) versus potentially more effective but riskier treatments.

Siminoff and Fetting (1991) identified three sets of factors that influenced the patient's rejection of a physician's primary treatment recommendation: (1) the information received concerning the benefits of the treatment was more specific, and women rated the side effects to be more severe; (2) they perceived the strength of their physician's treatment recommendation as weaker than other physicians; and (3) they were better educated and more likely to be risk takers. It seems that the more patients knew and the less sure the physician appeared, the more likely patients were to diverge from treatment recommendations. The investigators acknowledged that they did not control the information that physicians gave to their patients, and they indicated that physicians provided less explicit information about treatment options to patients with less formal education.

Summary

The human ecological framework aids in the depiction of the decision making process concerning breast cancer treatments that may or may not bring a woman's body and life back into a state that is ordered and organized. The woman with breast cancer is faced with the challenge of deciphering information about the physiological factors that caused the imbalance in her human biology. Human biology identifies high-risk individuals through genetics, hormonal influences, screening, and tests concerning tumor composition and the immune system (Murphy, 2000). If a woman's breast cancer is narrowly classified as a disease, the prescribed treatment will be interventions aimed at altering the biological structure (Thorne & Murray, 2000). Then she must choose options such as invasive surgery and/or toxic medication and radiation based on the predictable risks of surviving (Nugent, 1995). In this manner she will attempt to regain control of her body and life in a meaningful and comprehensive manner.

Several decision making theories have been reviewed and all identify the criteria for making a quality healthcare decision. These factors range from the acceptance of information to avoidance of discussion and denial of the problem. Quality of life was considered as the woman copes with her decision to accept or decline therapies that her physicians have prescribed. However, it is not clear from the literature what physiological and psychological factors influenced women in arriving at a decision that is not in accordance with the prescribed therapies. It is important to examine the relationships and the socio-political environments that affect the women's decision making process.

External Environment

Patients are influenced by relationships with their social network and their healthcare providers, and they make health care decisions within the context of public and private institutions. This section of the literature review will examine the external environment, which encompasses the relational (microenvironment) and contextual (macroenvironment) factors within the human ecological framework that influence the women's decision making process (Westney et al., 1988).

Relational Factors

Human ecology approaches breast cancer as an illness, an innately human experience of symptoms and suffering: "Illness is how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (Sherwin, 1996, p. 200). However, illness also has a tendency to make patients dependent on others and reduces their autonomy (Illich, 1975; McKnight, 1982). This places patients at risk of being manipulated and even coerced into overriding their own preferences (Sherwin, 1998). The challenge is to provide an environment that will give the woman the ability to manage her own problems, and an ability to influence and control her own decision making process.

Family Involvement

Women do not make their informed choice decisions in a vacuum. They deal with many factors in their homes and community environments (Stanton et al., 1998): the likelihood of cancer cure or recurrence, self-evaluation, likelihood

of additional treatment, partner support, attractiveness to partner, and their maternal role in the family. Single mothers may have the sole responsibility for their children's financial and emotional stability to consider when they are faced with months of debilitating chemotherapy treatments. Media reports, and opinions and cancer experiences of family and friends influence women. For example, Stanton et al. found that women may call upon the knowledge of treatment outcomes experienced by close others. The extent that they feel physically threatened by their illness will also influence their decision (Stanton et al., 1998). Furthermore, Verheggen, Nieman, Reerink, and Kok (1998) found that the woman's personal trust in the medical environment affects her decisions concerning her cancer treatment regime. Studies on informed choice need to be viewed from the woman's eyes since she is going to have to live or die with her decision.

Klein and White (1996) call the family 'the immediate ecosystem' where humans grow and adapt, and each family is embedded within a larger kinship network. All social systems are dependent on the production and consumption provided by a family's members, and at the same time, the family members are affected by their interactions with the social and economic systems. However, it is not necessary to focus on a 'family consumption unit' to scientifically determine family resource management and decision making. Researchers such as Bubolz and Sontag (1993) rejected science as the appropriate model for examining knowledge and practice, in favor of a hermeneutic approach that includes the subjectivity of experience and valuing. This hermeneutic interpretation of the

family ecosystem, according to Guba (1990), elicits individual constructions of the environment that reflect the continual adaptation of humans to the constant currents of change.

A family ecosystem perspective is an appropriate context for examining the informed choice process experienced by women with breast cancer. Cancer is linked to nature, culture, family, society and the self, which are all areas that human ecology embraces. Each woman is situated within a family environment that interacts with other larger environments, and change is inevitable. Changes are apt to raise problems and hence, problem solving is a rational means of meeting daily issues. Polk (1995) argues that the main assumption of most of the work associated with a human ecological perspective is the existence of an environmental crisis. A diagnosis of breast cancer creates a crisis for the women, their families and their community. Families are challenged to adapt and to accept new formulations, and if family members can accept the dynamic nature of their environments, and believe that problems are to be expected, trying to resolve them can perhaps be viewed as less disabling.

Environments do not determine human behavior, but pose limitations and constraints, as well as possibilities for humans. Families have varying degrees of control and freedom with respect to environmental interactions. Paolucci, Hall, and Axinn (1977) found that family decision making is the central control process that directs actions for attaining individual and family goals. Paolucci et al. argue that autonomy is fostered and a kind of security is developed within the individual when the family makes their daily decisions. Badir (1993) created a mental

picture of the daily modifications of a family's reality: "Every member of every family lives each day differently. When all the interactions come together at the end of the day, it is a different group of people who are interacting. ...There is a great potential for conflict when that family comes together again in the evening" (p. 8). Adjustment is a natural consequence of the daily changes. Bubolz and Sontag (1993) state that collectively, decisions and actions of families have an impact on society, culture, and the natural environment.

Contextual Factors

The contextual factors within the women's integrative ecological framework include the informed consent process, the influence of health care providers, and socio-political issues that affect the women's decision making process.

The Informed Consent Process

The informed choice process was initially developed to protect the human patient from the hazards of research and therapy in medicine (Calder, 1994). Historically, the content of the discussion with physicians focused on issues of trust and power. In cancer care, it was once standard practice to conceal the actual diagnosis from the patient. Beauchamp and Childress (1994) found that patients were not always told the whole truth in relation to diagnosis, treatment, or prognosis and often did not share in decisions regarding treatment. Today, the physician has a duty to meet all the standards of care: the technical and scientific aspects of medicine and the human and ethical concerns (Smith & McCarty, 1992).

When physicians are giving recommendations to their patients, they are obliged by law to (1) disclose the risks and benefits of the procedure, (2) communicate so that the patient can understand, and (3) ensure voluntary choice by the patient with no undue inducements (Nelson-Martin & Rich, 1999; Smith & McCarty, 1992). If the patient is partaking in clinical trials, the physician must disclose potential conflicts of interest on the part of the clinician-investigator, the unproven nature of the research, and the alternatives to participation in the therapy/research (Arras & Steinbock, 1995; Daugherty, 1999). At the same time, the physician must ensure that the patient understands her/his illness, the effect this illness will have on her/his life with treatment or without treatment, and the many costs to treatment measured not only in pain, physical dysfunction, and emotional distress, but also in dollars (Smith & McCarty, 1992).

The basic ethic of respect requires that providers ensure informed choice: the right to obtain complete, current information about diagnosis, proposed treatments, prognosis, risks and benefits of all treatment alternatives; and to present information in terms the patient can understand (Dunn, 1999). While, the informed choice process may be stressful for the medical 'expert' who must relinquish the final decision to their client (Carroll, 1998), it is now compulsory to adequately inform competent persons, and their subsequent decisions are binding on all providers (Dossetor & Cain, 1997). It is also imperative that consent is seen as on-going and must be maintained (Dossetor & Cain, 1997). If a competent person refuses any or all treatment after being adequately informed, "Their decisions are binding on all providers" (Dossetor & Cain, 1997, p. 35).

In the traditional medical model of informed consent, a provider transfers information to a patient (Gafni, Charles, & Whelan, 1998). After considering the information, the patient conveys his or her decision back to the provider. In oncology, Varricchio and Jassak (1989) observed that the complexity of treatment regimens, potential system toxicities, and the chronicity of the disease process have fostered the development of a multidisciplinary team approach to the information exchange involving oncology patients. The patient is the one member of the team who has the least medical expertise and who may be perceived to have the least credibility.

Recently, Nelson-Martin and Rich (1999) have observed the decline of the once predominant physician-oriented model of medical care where it was believed that the doctor and not the patient, should define the nature and boundaries of patient problems. The healthcare provider and the patient are individual human beings who are interacting within their physical and social environments, and more specifically within the existence of an environmental crisis (Westney et al., 1988). However, the difficulty with the development of an informed choice process that will reflect this changing environment, is that the conceptual frameworks were all chosen from pre-existing theoretical models. These models do not reflect the increase in patient's accessibility to information (Turner, Maher, Young, Young, & Vaughan Hudson, 1996), and the predictive capabilities of these models may no longer be valid representations of the phenomenon of interest.

Health Care Providers

Health care providers (HCP's) still have the power to control information through their management of the information-giving process. The women in Stafford et al.'s (1998) study reported that the surgeon was the most influential factor in the treatment decision. The surgeons had assumed incorrectly that woman's preference for mastectomy was due mostly to the inconvenience of radiotherapy (Stafford et al., 1998). Factors that were second to the surgeon's recommendation were concerns over radiation, duration of treatment, and travel restrictions. Bilodeau and Degner (1996) reported that women in their study preferred and actually received the most information from their physicians (96%). Their three most important needs were having information about the stage of disease, the likelihood of cure, and the treatment options available to them. Most women in Kraus's (1999) breast cancer group (77%) reported having a choice regarding their breast cancer surgical treatment. Their sources of information included the surgeon (50%), reading material (42%), family and friends (30%), and other women with breast cancer (10%) (Kraus, 1999).

Miyaji (1993) revealed that the way doctors control information is closely related to the way they handle their clinical practice, as indicated by the following factors: the physicians' own emotional coping style, institutional and legal constraints, and power relationships among patients, doctors and other care-givers. Berry, Dodd, Hinds, and Ferrell (1996) stated that information is often presented by physicians in a manner that will ensure that their study is representative and contains enough participants. Pape (1997) stated that the

reasons given for ensuring that all elements of informed consent are satisfied, are to reduce malpractice claims, provide greater patient satisfaction, and improve the professional image.

Studies indicate that some physicians are comfortable saying, "If you were my mother (wife), I would recommend ...,", whereas others decline to make a specific recommendation (Reaby, 1998). Further, McNeil, Pauker, Sox, and Tversky (1982) demonstrated that patients and physicians make different treatment decisions as a function of whether outcomes are framed in terms of survival or mortality probability. Their investigation revealed that the attractiveness of surgery for lung cancer, relative to radiation therapy, was substantially greater when the treatments were identified rather than unidentified, when the information consisted of life expectancy rather than cumulative probability, and when the problem was framed in terms of the probability of living rather than in terms of the probability of dying.

Before a physician presents his patient with an informed choice concerning selected therapies, he may have already made assumptions about her ability to pay for drugs (e.g., anti-nausea medications), the likelihood of her living long enough to benefit from the treatments, or the chance of being sued for not ordering specific tests (Shinagawa, 2000). McKinlay et al. (1997) studied the influence of these different factors on a physician's clinical decision making behavior in the evaluation and treatment of breast cancer. They found that age, socio-economic status, culture, comorbidity and assertiveness were all factors that influenced the treatments that were recommended. Data show that treatments are

influenced by race, socioeconomic status, physical attractiveness, intelligence, and gender; those with less power generally get less assiduous care (Smith & McCarty, 1992). Walker, Kohler, Heys, and Eremin (1998)reported that elderly cancer patients were often not given standard doses of chemotherapy when in fact these doses would have been well tolerated by those particular elderly patients.

The physician is obligated to try to understand the patient's values, culture and lifestyle, and help them to choose what they want, not what the health care provider would want or do in the same circumstances (Beauchamp, 1982). However, when delivering the treatment options available at a specific institution, the physician may not elaborate on all of the social implications of the therapies (Gregory & Russell, 1999). For example, health care providers thoroughly describe the physical effects of chemotherapy: obesity, inconvenient hot flashes as a result of premature menopause, and the familiar baldness associated with a deadly disease (Nugent, 1995). However, chemotherapy also takes women away from their nurturance roles and places them in a position where they feel they are a burden on others. The effect on the patient's employment and inability to obtain insurance for the rest of her life are issues that rarely arise when asking for informed consent (Batt, 1994). The recognition that sometimes there will be divergent priorities for desired treatment outcomes between physician and patients requires acknowledgement of the limitations of medical science (Barnes, Davis, Moran, Portillo, & Koenig, 1998).

Bok (1978) challenged two common physician claims: that patients do not want bad news and that the truth may be harmful. Bok noted that medical oaths do

not stress the ethical principle of veracity, but that studies have shown that most patients want to know the truth. Nelson-Martin and Rich (1999) believe that in the last two decades, these two approaches to withholding information have diminished and patients are better informed regarding diagnosis, treatment, and prognosis. Turner et al. (1996) have introduced a countervailing ethic of informed consent that embraces the concept of user participation. Since patients do not necessarily share doctors' priorities in decision making or place the same emphasis on different types of morbidity, it is imperative that health care providers understand their patients' perspectives and priorities.

Socio-political Issues

Power, politics, fundamental world views and economics all play large roles in driving cancer research and treatment policies (Batt, 1994). Increasingly, government and other third-party payers are defining the treatment options available to both patients and physicians (Sherwin, 1998). Institutions are concerned with setting research agendas and allocating economic and health-care resources (Sherwin, 1996). National breast policy derives the framework for breast cancer treatment based on the statistical results of treatment protocols, in which some significant number of women with some similar characteristics may respond (Wooddell & Hess, 1998). The problem is that there are not enough variables applied to an individual's recommendation. An individual's innate ability [and need] to cope is limited by the illusion of choice in a society that is exercising dominating behavior. The woman is being socially encouraged to choose from a limited set of similar options, resulting in the perpetuation of the

very mechanisms that ensure compliant medical consumers (Sherwin, 1998). The impacts of such a system limit the woman, and have a widespread impact on social processes and indeed on the entire culture. Foucault (1972) implies that those who have knowledge have power, and that those who have power control the ability to gather and disseminate knowledge. Only by acknowledging these external influences will women with breast cancer play a larger role in gaining knowledge, even in the complex cancer treatment arena.

Socio-political Marginalization

The market, media, family and medical science blame individuals for neglecting their responsibility concerning the detection of breast cancer (Gordon, 2000). Nugent (1995)argues that when the society within which an individual lives blames the woman for her personal behaviors (e.g., smoking or eating a high fat diet), they are excused from accepting responsibility for the individual. Gregory (1999) commented on how women who receive a diagnosis of breast cancer accepted responsibility for "contributing cancer to the future generations of women in her family" (p. 26). Actually dying from cancer is replete with failure: the concomitant failures of medicine, the woman's body, and the 'will' to win the war against cancer (Baum, 1997; Gregory & Russell, 1999; Springer, 1996). This societal blaming defines the women's role in taking responsibility for her disease.

While the environment may have caused a woman's breast cancer (pollution, food consumption patterns, personal habits, and/or genetic coding), the burden of both prevention and treatment of cancer rests with the individual. The preventive focus is overwhelmingly concentrated on individual lifestyle issues

and not on the sort of prevention that can only be achieved by instituting broad social and political action (e.g., rigid pollution controls). Women and their families coexist within the same environment, so the women's cancer may indicate a threat to the safety of the individuals that surround her. Sherwin (1996) emphasizes the need to expand the investigation of cancer beyond the private tragedy of an individual in order to influence the broader social and political perspective: "We must place a priority on exploring ways to improve the environment we inhabit and the conditions people are forced to live under, rather than concentrating on identifying and surgically altering individuals who may become ill within a hazardous environment" (p.196). Human ecology seeks to enhance people's quality of life and well-being by exploring the connection between the behavior and health of people and the quality of their environment. This could be accomplished by transforming some of the energy that is associated with fear of cancer, disease, and death into supportive actions for needed changes in the social conditions that now support the spread of this disease (Sherwin, 1996).

Sherwin stated that individuals may be marginalized by their feelings of social and intellectual inferiority in comparison with their physicians, which limits their ability to ask or even formulate questions. According to several studies, if you couple oppression with culturally induced reverence of the medical profession, the informed consent process is reduced to a respectful acceptance of the recommended treatment (Hern, Koenig, Moore, & Marshall, 1998; Stanton et al., 1998; Turner, 1998). Sherwin (1998) suggests a more politically sensitive

approach than focusing on ways to make the patient understand the informed consent document: "A richer, more politically sensitive standard of autonomy should make visible the impact of oppression on a person's choices as well as on her very ability to exercise autonomy fully" (p. 33). Shinagawa (2000) recommends that we as a society must investigate institutionalized racism or we will never be able to change the system that is responsible for racial and ethnic disparities in health. Health care services must be provided on the basis of just and equitable distribution to everyone, regardless of their circumstances.

Summary

Individuals are not isolated units. Human experience is rooted in building and maintaining personal relationships and communities. Even survival rates are affected by the social context and social support from one's partner, family, friends, relatives and health care providers (Carlsson & Hamrin, 1994). The informed decision making process for women with breast cancer is an interactive process of negotiating statistics, experience, and relationships. All exchanges and negotiations with family, health care providers, and community have the potential to shape the woman's final decision concerning her breast cancer. The physician's role in influencing the shift of control in the decision making process from the health care provider to a negotiated process was examined. Since a person's actions are responsive to, and connected to others and to the socio-political environment, inequality and detachment issues were examined because they may affect participation in the informed consent process.

III. THE METHOD OF INQUIRY: GENERAL

Introduction

Research design reflects the nature of the phenomenon being examined, and the pre-existing theories concerning that phenomenon (Field & Morse, 1985). Qualitative research is particularly suited for interpreting a phenomenon in terms of the meanings people bring to that phenomenon (Denzin & Lincoln, 2001). In the statement of purpose for this study, the research of interest was identified as being the experience of refusing adjuvant breast cancer therapies, and the context within which the decision was made. In order to understand the experience of refusing adjuvant therapies from the women's point of view, it is necessary to have individual women describe their worlds and to discover patterns in their perceptions and behaviors that will generate theories about that experience. Creswell (1998) emphasized that qualitative research has the potential to present a "complex, holistic picture" to the reader. The focus of qualitative research is on the meaning of the experience, on the context of the experience, and on individual differences in responding to the experience.

Quantitative researchers search out data or evidence to prove or disprove hypotheses, using a few variables and many cases. In qualitative research, the abstractions are developed by grouping together the many variables that have been gathered from a few cases (Bogdan & Biklen, 1992). The proposed research involves a small group of women who have chosen to refuse adjuvant breast cancer therapies. The researcher is required to systematically generate a theory from data that are obtained from the participants' realities (Glaser, 1978).

Grounded theory methodology is the qualitative method selected as the most suitable to satisfy the purposes of identification and explanation of the experiences of women who refused adjuvant breast cancer therapies, and the context within which they made their decision. First, the grounded theory method and its philosophical and theoretical perspectives are examined. Second, the constant comparison method of data collection and analysis, and memo writing are described. Third, the trustworthiness issues of credibility, transferability, dependability, and confirmability are addressed.

Grounded Theory Methodology

In the early 1960's, two sociologists, Glaser and Strauss (1967), introduced the grounded theory method. The primary purpose was to address issues within sociology by systematically gathering and analyzing data for the purpose of generating theory that respects and reveals the perspectives of the subjects in the substantive area under study. Several qualitative theorists (Glaser & Strauss, 1967; Strauss & Corbin, 1998; Wuest, 1995) argue that grounded theory is inductively derived from the study of the phenomenon it represents, designed to discover dominant processes that can predict and explain relevant behavior, resulting in a theory that is conceptually dense. This theory is articulated toward the end of the study and can assume the form of a narrative statement, a visual picture, or a series of hypotheses or propositions (Creswell, 1998).

The philosophical foundation for grounded theory is symbolic interactionism, which focuses on the "inner or experiential aspects of human

behavior" (Chenitz & Swanson, 1986). Important theorists of symbolic interactionism are Mead (1934) and Blumer (1969). Mead's contribution was his description of the process of the development of the sense of self. Blumer focused on the concept of 'meaning' as the guide for human behavior (Robrecht, 1995). Symbolic interactionists suggest that humans order their world through continuous processes of negotiation and renegotiation (Morse & Field, 1995); by making reflexive use of symbols (Blumer, 1969); and by eliciting meanings in situations according to their beliefs, rather than by simply reacting (Morse, 1992). Individuals interpret and define symbols, and in doing so, they actively create and share the meaning of those symbols. This individual interpretation of symbols can only be understood by having the researcher enter into the defining process through such methods as participant observation or unstructured interviews (Morse).

The primary purpose of grounded theory is to generate explanatory theories by moving from the description of behavior to the explanation of patterns at a conceptual level. The method must reflect that people constantly create and modify symbolic meaning within their environment. Subsequent behavior, with its consequences, can only be understood in context and as part of ongoing process. Grounded theory allows the researcher to encompass the changes during the refusal process, and describe the stages of this experience. The assumptions of grounded theory are consistent with the experience of women with breast cancer and refusal of adjuvant therapies. Women are influenced by their interactions with

family members, health care providers and the world in which they live, and they in turn interpret the meaning to the researcher.

Constant Comparison method

One way to ensure validity of findings in grounded theory is by the use of the constant comparative method (Glaser, 1978; Strauss & Corbin, 1998). In this approach, the data collection, theoretical sampling, and analysis all occur concurrently as the study progresses, and sampling and further data collections are based on the emerging theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The process of coding, sorting, and integrating data ensure conceptual development and theoretical density (Strauss, 1987).

The process of data analysis in grounded theory research is systematic and follows a standard format (Creswell, 1998). Grounded theorists begin with general questions, and through a process of elimination of inappropriate questions and the introduction of emerging relevant questions, rich and complete data are collected (Strauss & Corbin, 1998). The data are initially organized through open coding procedures to see new relationships between events, actions and interactions (Creswell, 1998). Each interview is examined line by line and assigned in vivo codes (Hutchinson, 1986). The in vivo codes are the actual words of the participants, which prevents the use of the researcher's preconceived impressions. Open coding attempts to break down data and reconceptualise it (Rice & Ezzy, 1999). Rice and Ezzy suggest including 'noting patterns and themes' and 'making methaphors' to add richness and complexity to the

processes. Open codes are then clustered into categories on the basis of similar meaning, both conceptually and theoretically (Chenitz & Swanson, 1986).

In axial coding, the codes are dissected to ensure that each one is fully elaborated and delineated according to specific properties (Strauss & Corbin, 1998). The researcher puts those data from open coding back together in new ways: more central categories become evident; other categories combine and change position in the emerging structures and events (Strauss & Corbin, 1998). Two processes similar to axial coding are described by Rice and Ezzy as 'partitioning variables', and 'subsuming the particulars into the general'. Glaser's (1978) strategy for this coding paradigm involves asking questions in accordance with of "The Six C's": causes, context, contingencies, consequences, covariances, and conditions. Creswell (1998) outlines the steps of analysis:

> The researcher identifies a central phenomenon (i.e., a central category about the phenomenon), explores causal conditions (i.e., categories of conditions that influence the phenomenon), specifies strategies (i.e., the actions or interactions that result from the central phenomenon), identifies the context and intervening conditions (i.e., the narrow and broad conditions that influence the strategies), and delineates the consequences (i.e., the outcomes of the strategies) for this phenomenon. (p. 57)

The development of a significant process, relationship, event, or issue into a category will provide the basis for subsequent data collection based on the participants' experiences and their construction of those experiences.

The subsequent processes involved in selective coding are much the same as in axial coding, but at a higher level of generality. Through the process of selective coding, the conceptual categories are collapsed and unified around a core category or variable, that provides a theoretical point of integration for the study (Corbin & Strauss, 1990). The core variable has three essential characteristics: "it recurs frequently in the data, it links the various data together, and it explains much of the variation in the data" (Hutchinson, 1986, p. 118).

The process of theoretical sampling of successive informants is based on an assessment of factors believed to have an impact on the process of interest as well as on new factors that emerge from the analyzed data. The researcher collects new data to "check out, fill out, and extend theoretical categories" (Charmaz, 1990, p. 1163). The number of passes one makes to the field depends on whether the categories of information become saturated and whether the theory is elaborated in all of its complexity (Hutchinson, 1986). Further theoretical sampling of the literature as a source of data, use of secondary informants, and constant memo-writing assist in forming and confirming discovered categories and inter-related processes. The core category forms the basis for the emergence of the Basic Social Process (BSP): "The BSP must explain all variations in the problem being studied, predict behaviors, and show how these processes may evolve over time" (Morse & Field, 1995, p. 161).

The result of this process of data collection and analysis is a substantive-level theory, written by the researcher close to a specific problem or population of people. The explicit set of analytic guidelines and procedures created by the

qualitative researcher reap fruitful conceptualizations of her/his data (Charmaz, 1990). In Charmaz's view, "a theory explicates a phenomena, specifies concepts which categorize the relevant phenomena, explains relationships between concepts and provides a framework for making predictions" (p. 1164). Future research can subject this theory to further empirical testing because the variables or categories are known from field-based data. The primary outcomes of this study will be a theory with specific components: a central phenomenon, causal conditions, strategies, conditions and context, and consequences (Creswell, 1998).

Memo-Writing

Memo-writing by the researcher will occur throughout the analysis, in the form of a journal of experiences, theoretical concepts, analytical insights, and diagrams of relationships (Morse & Field, 1995; Rice & Ezzy, 1999; Strauss & Corbin, 1998). Basically, memo-writing is the written copy of the researcher's inner dialogue about emerging ideas, hunches, questions, and elaborated categories. These captured insights are discovered during the analysis of the processes and assumptions that occur during data collection and analysis. The researcher dissects the data from a variety of perspectives and defines what is implicit and what is explicit (Strauss & Corbin, 1998). Memo-writing will also allow the researcher to see the distinction between herself and the topic being researched. Since the memos are considered public domain, care must be taken concerning confidential information.

The researcher then takes this repository of ideas, and reorganizes, deletes, and reconceptualizes the interpretations. The objective is to present the

memos in a cohesive manner, as part of the data. In a larger sense, a researcher may continue to make theoretical discoveries, as the memos become increasingly conceptual. Therefore, the later memos may include, incorporate, and transcend existing theory, as the researcher develops her grounded theory (Strauss & Corbin, 1998).

Trustworthiness

Trustworthiness or scientific adequacy of research is an active part of judging the quality of the grounded theory research process. There are conditions designed to ensure that the theory 'fits' with reality, confers 'understanding', and provides practical and theoretical 'utility'. These conditions are based on truth value, applicability, consistency, and neutrality (Lincoln & Guba, 1985). Lincoln and Guba offer companion terms for qualitative, or naturalistic, investigations: credibility (internal validity), transferability (external validity), dependability (reliability) and confirmability (objectivity).

Credibility

Credibility refers to confidence in the truth of the findings: a vivid description of the experience so that it provides a logical representation of the social reality for the participants and any others who have experienced the phenomenon. According to Glaser and Strauss (1967), to ensure credibility the reader must be convinced of the description, the supporting data should be explicit, and there should be sufficient detail about the similarities and differences among the comparison groups. The latter is critical to judging the theory as legitimate for the social world in which it is applicable.

To establish credibility, a number of useful practices are suggested. First, spend extended time in the field to overcome distortions introduced by the inquirer's presence, and to provide time to identify salient characteristics of both the context and the phenomenon (Strauss & Corbin, 1998). Accuracy of the data is enhanced by returning to the participants with literal transcriptions of their interviews for clarification of content, and expansion of incomplete material (Morse, 1991). However, the researcher must document the ways that the inquiry was altered as a result of the participant's examination of their interview and its interpretation. Second, use the constant comparison method to gain a high degree of familiarity with the data, to appreciate atypical but critical characteristics, and to eliminate irrelevant material. Open coding compiles data into categories, and then axial coding interrelates these categories. The researcher looks for recurring actions and interactions, and considers counter arguments and interpretations before returning to the field, thereby verifying the data (and prolonging the engagement with participants) (Lincoln & Guba, 1985). Because participants are interviewed repeatedly about the same material, the investigator is in an excellent position to pick up misinterpretations in coding. Third, take into account all rival explanations and negative or atypical cases (Field & Morse, 1985). The identification of atypical cases assists in augmenting and extending the emerging theory by introducing instances when the theory does not apply. Fourth, peer debriefing provides opportunities to test the researcher's insights against those of uninvolved peers. Another experienced researcher reads randomly selected transcripts and independently identifies major categories. This coding is then

compared with the researcher's data reduction to increase the validity of the interpretation of the results (Appleton, 1995). Peers also impart advice about important methodological steps in the emergent design, and perform a debriefing function for the researcher (Lincoln & Guba, 1985). Finally, material related to the phenomenon being studied should be collected and examined only after analysis of the main data sources has occurred, in order to reduce being influenced by previous research (Lincoln & Guba).

Transferability

Transferability deals with the generalizability of findings to a wider population. Theoretical sampling is used to maximize the range of information that is collected. The participants are initially selected according to their experience, willingness to share, and ability to inform or illuminate the phenomenon. Since further participants are selected on the basis of findings that emerge from the study, the typical and atypical aspects of the phenomenon will be represented. The result is 'thick description' that provides enough information about the context to impart the experience of the phenomenon (Creswell, 1998). Thick description also facilitates judgements about the extent to which working hypotheses generated from that context might be transferable to a second and similar context. While, Morse (1991) contends that a qualitative research project should stand on its own as a complete study, the development of a substantive theory is regarded as a foundation for future research.

Dependability

Rather than reliability, qualitative researchers seek dependability: that the data will be accurate and comprehensive (Bogdan & Biklen, 1992; Creswell, 1998). The qualitative researcher must document and defend all design decisions so that the reader has access to that information when judging the study and when contemplating a comparable investigation (Marshall & Rossman, 1989). Testing rival explanations or hypotheses by organizing the data in different ways and then analyzing the data from alternative perspectives demonstrates why the methods that were selected are most appropriate for the particular study (Patton, 1990). While similar themes may be identified in subsequent studies, Rice and Ezzy (1999) suggest that each researcher's framework of understanding will still reflect their unique "geographical location, disciplinary training and biographical history" (p. 37).

Confirmability

The grounded theory researcher looks to confirmability rather than objectivity in establishing that the findings are a function solely of respondents and of the phenomenon in question. The research must be as free as possible from the biases, motivations, and perspectives of the researcher. Both dependability and confirmability are established through an auditing of the research process. An audit will verify that each finding can be appropriately traced back through the analysis steps to the original data. The use of verbatim transcripts of interviews provides evidence of the original source, and allows other researchers to inspect and assess the author's interpretations of the data (Glaser & Strauss, 1967; Rice &

Ezzy, 1999). Lincoln and Guba (1985) proposed that the report of a study should be auditable by another person who can follow the "decision trail" through clear information about the progression of events and about the logic of what was done and why. The strategy involves extensive documentation of the process and products of the inquiry. This requires a clear audit trail: ordered and dated field notes will place interviews within context; memos must record changes in the methodological approach; and the reason and time that changes where made to interview questions must be documented (Morse & Field, 1995). The reader can check that interpretations of the data clusters are reasonable and meaningful. In addition, the researcher will be required to develop detailed descriptions of her theoretical biases prior to data collection to ensure protection against interviewer bias (Patton, 1990). Bias can then be detected by comparing the early theoretical position of the investigators with the final theory.

Researcher's Orientation to Breast Cancer

I have been involved in health care as a dental hygienist and assistant professor in the Faculty of Medicine and Dentistry. Five years ago I discovered a breast lump, had a mammogram, biopsy, and subsequently a mastectomy. I read medical journals, talked to peers at the cancer clinic, and shared my findings with my family and friends. I was prepared for the oncologist's decision and agreed that chemotherapy was appropriate. However, due to severe complications with my blood counts I chose to terminate the chemotherapy. I also decided that tamoxifen posed too great a risk for me due to my previous health history. My curiosity lead me to interview women who had the courage to question the norm.

IV. THE METHOD OF INQUIRY: APPLIED

Data Collection Methods

The aim of this grounded theory was to generate explanatory theories by moving from the description of women's refusal of adjuvant therapies to the explanation of patterns at a conceptual level. These women described their experiences of information seeking and provided their perceptions of factors that were constantly being created and modified as they struggled with their decision concerning breast cancer therapies. Subsequent behavior, with its consequences, can only be understood in context and as part of ongoing process. Grounded theory was used in this study to facilitate the discovery of an in-depth perspective on the decision making process of women who refuse breast cancer therapy.

In this section, specific details will be described concerning the sample, the selection protocol for accessing participants and the procedures used for collecting the data. In grounded theory, the processes of coding field notes, memo-writing, sorting, saturation, and conceptualization that are carried out are defined within the specific parameters of this particular study. Finally, the ethical considerations will be addressed.

Description of the Sample

The participants in this study were 17 women who were willing to describe and share their experiences of refusing adjuvant breast cancer therapy. Participants were selected on the basis of age, the ability to understand the nature and purpose of the study, and the ability to express ideas on the subject. They were all residents of Canada and English speaking. Ten of the participants learned

about the study from posters in community based locations, or from contacts who saw the posters when they attended the community-based locations (see Appendix D). Three women were informed of the study by their alternative health care providers. Two women were informed by colleagues of the researcher.

A grid was designed to facilitate an ongoing analysis of the characteristics of the participants and ensure theoretical sampling. This process involved seeking out new comparison groups of women and asking them different and evolving questions to flesh out the emerging theoretical understanding. Since there is a higher incidence of breast cancer among women who live in religious communities, two women were recruited from different religious communities. Participants were also chosen that had modified their radiation therapy and who had refused both prescribed therapies and did not seek alternative therapies.

All of the women who participated contacted me on their own initiative after they were informed about the study. This method of recruitment protected the informant's identity from the researcher until the participant made the decision to make the initial contact. Each participant was given a pseudonym, and the first letter of the name corresponds to the order in which the interview occurred (e.g. Audrey = 1st interview). The pseudonym was chosen to match the origin of the participant's given name in an attempt to preserve a sense of the woman's persona.

Only two women who expressed interest in the study were not included. The first woman, who had the pseudonym Nicole, assumed that her lymphatic cancer had metastasized from pre-existing breast cancer. However, she had

Table 5: Participant Characteristics

Women	Mari-tal Status	Age at Dx	Years Since Dx	Education	Occupation	Kids To 20	Kids Over 20	Gra -nd Kid
Audrey	M	40's	1	Bachelor	Mother/ Teacher	4		
Bernice	M	50's	2	Graduate	SpiritualD /Teacher		3	5
Carolyn	M	40's	2	Tech College	Oral Health /Teacher	1	1	
Dominic	M	40's	1	College	Mother/ Secretary	4	1-step	
Ellen	M	40's	3	High School	Fitness Expert	1	2	2
Faith	M	40's	1	Graduate	Nursing		2	
Geneva	M	60's	6	Graduate	Teacher		3	2
Helga	W	60's	1	High School	Nursing Home		3	5
Irene	M	50's	3	Bachelor	Teacher		2	2
Jocelyn	Dnow M-then	60's	3	College	Nursing Home		3	1
Kim	M	30's	4	Bachelor	Manage-ment/ Scientist		2-step	
Liz	M	40's	9	Graduate	Spiritual Director		2	2
Michele	M	30's	1	Graduate	Teacher	3		
Odette	S	50's	6	Graduate	Spiritual D/Teacher			
Pamela	M	50's	2	High School	Office Manager		1 1-step	
Querida	Dnow M-then	40's	1	Bachelor	Office Work	1		
Roseann	D	60's	3	Graduate	Spiritual D/ Nurse		1	1

Spiritual Director (Spiritual D): Employed by a religious organization to facilitate spiritual programs.

refused all medical intervention, including mammography, biopsies or surgery to confirm the diagnosis of breast cancer. Since confirmation of breast cancer was a criterion for sample selection, she was not included in this study. The second woman, who had also refused all medical and alternative interventions after the initial needle biopsy, continually cancelled her interview appointments due to co-morbidities, and finally her physician deemed her too ill to be interviewed.

Fourteen of the seventeen participants were married at the time they were diagnosed: two of these subsequently divorced. One woman was single, one divorced, and one was widowed. The women range in age from 37-69 years when diagnosed, and the average of the participants' ages is 52 years.

The majority of the women have a university education: seven have a graduate degree and four have a bachelor degree. Three women have college education and three have only high school education. The occupations fall into three categories: seven participants were teachers (two are currently spiritual directors), six were health care providers (one is currently doing spiritual work), and four worked in office/managerial positions.

Nine women have children who are all over 20 years of age; three women have children who are all under the age of 20; and three have children in both categories. Eight women have grandchildren. Two women have never had any child-births, but one of these women has 2 step-children.

Physiological Factors

The women discovered their breast lumps through self-examination, physician examination, mammogram, ultrasound, and/or biopsy (includes needle

Table 6: From Diagnosis to Surgery

Participant	Initial Discovery	Mammo-gram	Ultra-sound	Biopsy	Diagnosis-Surgery [1]	Unique
Audrey	GP exam	yes	yes	yes ✔	4 weeks	unrelated surgery 1st
Bernice	self	yes (clear)	yes (clear)	lump-her choice	2 wk/2 wk	lump 1st mast 2nd
Carolyn	self	yes	yes	yes-2w	4 weeks	
Dominica	self	yes	yes	yes ✔	6 months	altern 1st
Ellen	self	yes	no	yes ✔	2 days	
Faith	self	yes	no	yes-1w	10 months	chemo 1st
Geneva	mammo-gram	yes	no	yes ✔	6 days	
Helga	self	yes 1st clear, 2nd suspect	no	yes ✔	5 days	she asked to recheck
Irene	mammo-gram	yes	no	yes ✔	4 weeks	
Jocelyn	self	yes	yes	yes ✔	2 weeks	
Kim	self (Dr waited 4mo	yes (1st clear) 2nd after biopsy	yes	yes-4m	5 months	chemo 1st mast 2nd
Liz	self	yes	no	yes-3w	7 weeks	Dr on holidays
Michele	mammo-gram	yes	no	yes-3w	6 wk/ 3.5mo	lump 1st mast 2nd
Odette	self	yes	no	yes ✔	2 weeks	
Pamela	self	yes	yes	yes-2w	3 weeks	
Querida	self (2 yrs earlier)	yes (1st mammo-gram ever)	no	yes-1w	2 months	reconst-ruction consult
Roseanne	mammo-gram	yes	no	yes ✔	3 weeks	

Lump = lumpectomy Mast = mastectomy Altern = alternative

[1] This indicates the length of time from **diagnosis** until the **surgery** occurred.

✔ The biopsy occurred the same day or within days of the mammogram.

or core biopsies). As one woman remarked after her diagnosis, "That's when things got going" (Helga). The length of time from diagnosis of the breast tumor until the actual surgery varies for each woman due to unique circumstances surrounding their breast cancer experience (Table 6).

Twelve of the women discovered the breast lump through breast self examination (BSE), four during routine mammography appointments, and Audrey's family doctor found her lump. While all of the women had a mammogram, Bernice's, Helga's, and Kim's mammograms did not reveal any abnormalities. They insisted on further testing, and their biopsies tested positive for breast cancer.

Seven of the participants indicated that they had an ultrasound at the same appointment as they had their mammogram, and nine of the women had a needle and/or core biopsies the same day as their mammogram. The other women waited one to three weeks for a biopsy, except Kim, whose doctor observed the lump for four months, until Kim insisted on a biopsy.

There were huge discrepancies in the length of time between breast cancer diagnosis and surgery: the range was from 2 days to 10 months. Eleven women had their surgery within 4 weeks of diagnosis. Liz, Michele and Querida said they waited 2-3 months in order to obtain more information about therapies and reconstruction options. Kim and Faith had chemotherapy prior to surgery to reduce the tumor size and Dominique used alternative therapies in an attempt to shrink the tumor before she accepted surgery.

Prescribed Therapies and Alternative Therapies

Since the stage of breast cancer has an impact on treatment protocols and prognosis, it is listed in Table 7 beside the medical interventions for each woman: mastectomy, breast-conserving surgery (lumpectomy), axillary node dissection (lymph node), breast reconstruction (R), cytotoxin chemotherapy, radiation therapy, and endocrine therapy (tamoxifen) and alternative interventions.

Table 7: Surgery and Therapy

Participant	Surgery	Lymph Nodes	Stage	Chemo	Radiat	Tamox	Alter
Audrey	Lump	negative	1	no	yes	yes	no *
Bernice	Lu/Mast	positive	3	no	no	yes	yes
Carolyn	Mast	negative	2	yes	not req'	no	no *
Dominica	Mast	13/17 +	3	part	no	no	yes
Ellen	Mast	1/10 +	2	yes	no	no	no *
Faith	Mast	positive	3	part	yes	yes	no *
Geneva	Mast	negative	2	no	no	yes	no
Helga	Mast	1 +	2	no	no	yes	no
Irene	Lump	negative	2	no	no	no	yes
Jocelyn	Lump	negative	2	not req'	yes	no	no *
Kim	Mast/Re	1 +	2	yes	not req'	no	yes
Liz	Lump	no	1?	no	no	no	yes
Michele	Lu/M/R	1/16 +	2	no	no	no	yes
Odette	Mast/Re	negative	2	no	yes	yes	yes
Pamela	Lump	negative	2	not req'	part	part	no *
Querida	Mast/Re	negative	2	not req'	no	not req'	yes
Roseanne	Lump	negative	1	not req'	no	no	no *

* These women did take herbs and vitamins but they do not go to alternative practitioners concerning their breast cancer.

Nine of the women had a mastectomy, 6 women had breast-conserving surgery (lumpectomy), and Bernice and Michele had a lumpectomy first, followed by a mastectomy due to positive margins of breast cancer surrounding the lumpectomy site. Seven women had positive lymph nodes. Eleven of the women

had Stage 2 breast cancer at the time of the interview. Audrey and Roseanne were at Stage 1, and Bernice, Faith, and Dominica were at Stage 3. Liz told her surgeon to consider her at Stage 1 because she would not consent to having her lymph nodes removed.

The following table provides a summary of the treatments selected and rejected by the women in this study.

Table 8: Summary of Selected and Rejected Adjuvant Therapies

	Chemotherapy	Radiation	Tamoxifen	Alternative
1	no	no	no	yes
2	no	no	no	yes
3	no	no	no	yes
4	not required	no	not required	yes
5	not required	no	no	no
6	one	no	no	yes
7	no	no	yes	yes
8	no	no	yes	no
9	no	no	yes	no
10	no	yes	yes	no
11	no	yes	yes	yes
12	yes	not required	no	no
13	yes	not required	no	yes
14	yes	no	no	no
15	not required	yes	no	no
16	5/6ths	yes	yes	no
17	not required	3/5ths	1 month	no

To summarize, eight women refused all chemotherapy, Dominica terminated chemotherapy after one treatment, and Faith terminated her final chemotherapy treatment; ten refused radiation and Pamela refused 2/5th of her radiation. Nine women refused tamoxifen and Pamela terminated after one month.

Finally, eight women utilized alternative practitioners before, during and after their diagnosis and therapies. Liz, Michele, and Querida, used alternative

therapies exclusively after they completed their surgery for breast cancer. Dominica used alternative therapies for 6 months prior to her surgery; she terminated her chemotherapy after one treatment and resumed her alternative therapies. All of these women made it very clear that they thought it was important to remove the tumor because they felt alternative therapy was too slow: "I just had a feeling that it was going to take too long, and I didn't want to take the risk" (Querida). The alternative therapies used by the women in this study include homeopathic and naturopathic medicine ("gentle medicine"), traditional Chinese medicine and acupuncture ("ancient medicine"), massage therapy, major diet changes (alkaline, vegetarian diet), herbs and vitamins, immune boosting therapies, detoxification therapies, Reiki, visualization ("loving cells into wellness"), meditation, yoga, and Qi Gong. Their objective was to get their "body, mind and spirit all kind of in one piece again, instead of feeling fragmented". The women said that alternative therapists do not treat the woman for cancer, "they make the body the best place it can be, so that cancer and other diseases cannot survive in it" (Michele). All of the women stated that adherence to the strict alternative regimes diminished over time.

The Interview Process

At the beginning of the initial conversation, each participant was given an information sheet (Appendix A1) and the researcher explained the consent form and confidentiality policy and that at any time they preferred that something they said not be included in the transcript, their preference would be respected. They were also informed that they could drop out of the study at any time. The

participants were informed that all of the interviews would be transcribed and coded by the researcher and she and her thesis advisor would be the only persons who had access to the actual names of the participants. Then the participants were asked to sign the consent form (Appendix A2).

Data were collected by audio tape-recorded interviews. Thirteen women were interviewed once, and four women were interviewed twice. The data were collected between February 2001 and October 2001, with the majority of interviews conducted in February, March, and April of 2001. All but three of the interviews were conducted in the participants' homes, and all the participants chose a time that was convenient for them. Two women chose to be interviewed over the phone to overcome the inconvenience of traveling a long distance. One woman chose to be interviewed at her office, after business hours to ensure her privacy. Only two interviews lasted one hour, while the rest lasted from 2 to 3 hours. Second interviews were used to clarify ambiguous data, and to verify and expand on information obtained from the later participants.

In the intervals between interviews, tapes were transcribed by the researcher to increase familiarity with the themes that were arising. This proved advantageous, particularly towards the latter part of the data collection when coding and data analysis were well underway. The time span made it possible to reflect on the data and interviewing style and to discuss preliminary findings with the researcher's supervisor and committee members. The transcribed interviews yielded over 400 pages of typed transcripts; NUD*IST 4 software was used to

prepare data for qualitative data analysis (Qualitative Solutions and Research Pty Ltd., 1996).

Initial interviews commenced with general, informal conversation aimed at establishing a measure of support and trust with each participant. Once a level of comfort was established, the demographic information was gathered: the woman's age, marital status, number of children, occupation, and education. Then the woman was asked to begin her story by explaining how the breast lump was discovered. The interview proceeded by means of questions that lead to a general discussion of the research topic as it pertained to the woman's experiences. Women would carry on, after explaining how the lump was discovered, to describe the shock of the initial diagnosis, the need to make more appointments for biopsies and surgery. Then they described the period between their surgery and their appointments with the oncologists. They would weave in stories about their relationships with their doctors, husbands and family members during this time of discernment. At some point early in the interview, the participant was invited to comment further, if they had not already done so, upon their refusal of adjuvant breast cancer therapies.

Researcher participation was purposively kept to a minimum in order to maximize gathering accounts that accurately represented the participant's experience. Open-ended questions within broad domains were used (Appendix D), and the participant was only interrupted to offer support or to encourage elaboration and detail. As information was gathered in individual interviews, and themes and patterns emerged through analysis of data, questions became more

specific in order to "check out" and develop certain aspects of the findings. This technique minimized the need for re-interviewing on all of the recurring issues.

When participants were interviewed more than once, their transcripts were sent to them prior to subsequent interviews. The participant checked for accuracy of content, which allowed an opportunity to comment further on any aspect from the previous discussion. Names and other information deemed to identify the informant were excluded from the otherwise verbatim transcriptions. A note was inserted into the original transcription whenever a participant made any alterations or clarifications to her initial interview.

Data Analysis

The data collection, theoretical sampling, and analysis all occurred concurrently as the study progressed, and sampling and further data collections were based on the emerging theory (Charmaz, 1990; Glaser & Strauss, 1967). In grounded theory, the researcher begins by deciphering the behaviors and their consequences within a particular context and as part of an ongoing process. Patterns were conceptualized during the process of coding, sorting, integrating, and categorizing the data (Strauss & Corbin, 1997). Further dissection and reorganization of codes continued, along with the combining and shifting of categories, which lead to more abstract categories. The result of this process is a theory that respects and reveals the perspectives of the women who have made an informed decision concerning their breast cancer.

Discovering Categories

The data from each interview were transcribed into a format compatible with NUD.IST 4, computer software for qualitative research analysis. Following each interview, the tape was transcribed and preliminary thoughts about the data were recorded. All of the interviews were transcribed by the researcher. During the transcription, whenever the researcher anticipated a response from the participant that did not occur, the researcher inserted a bracketed memo documenting her bias concerning the responses.

The data were initially categorized by color-coding the data into major domains, a procedure referred to as "open coding" (Creswell, 1998): women's interactions within the medical context, information gathering strategies, support systems and their personal decisions. While much of the data could be placed into these large categories, subcategories and new categories became evident. The new categories were side effects of therapies and advice for women and health care providers (Appendix E). The main points of each interview were also summarized in a separate document for each participant. A grid was developed to facilitate identification between demographic characteristics (age, month/year of diagnosis, previous cancer experience, education level, occupation, children, stage of cancer, treatments taken and treatments refused, alternative/complementary medicine, and sources of information) and identified categories. The grid and the summaries provided a quick reference for each participant. This allowed the researcher to identify unsaturated categories, based on the emerging theory, and provided guidance regarding the selection of additional participants and participants with

whom a second interview would be beneficial. This "open-coding" process also allowed emerging relevant questions to be introduced in subsequent interviews.

From the initial "open coding" process, categories and subcategories were organized to correspond to the recurring sequences within the decision making process and a tree-structured index system was created in the NUD*IST program. All the data were transferred into the software program, and the interviews were reexamined line by line, using text units (each text unit consists of two lines of text), and assigned "in vivo" codes, meaning the codes were the participants' actual words (Hutchinson, 1986). In this stage of the data analysis, the data were assembled using "axial coding", where the codes were dissected further to ensure that each one was fully elaborated and delineated according to the specific properties that were constantly being defined and refined, another feature within the software program. The NUD*IST program was used to retrieve all occurrences of each code for comparison. The data from open coding were put back together in new ways: more central categories became evident; other categories were combined or changed positions in the evolving index system (Appendix F). The convergence of categories and the recognition of dimensions of concepts took the study to a higher conceptual level.

Linking Categories

Categories were linked using two major methods. First, Glaser's (1978) strategy was employed to examine "The Six C's". The researcher identified the central Cause: the discovery, diagnosis, staging, and surgical removal of breast cancer, and the perceived causes of the cancer. The Context included the health

care providers, the prescription of adjuvant and alternative therapies, and the women's support system. The previous experiences with cancer and alternative medicine were identified as intervening Conditions that influenced the refusal. The Contingencies involve the personal balancing of all the factors influencing the woman's decision. The sociodemographic factors were involved in determining the Covariances that were examined in the later stages of the data analysis. Finally, the researcher delineated the Consequences of refusing that involved the women, the health care providers, and significant individuals in the women's families and communities.

Another way that the categories were linked was through the process of "selective coding" (Appendix G). The conceptual categories were collapsed and unified around a "core" category (or variable). Because the focus of the research was on women refusing breast cancer therapies, 'justifying' became an important theoretical code. This core variable, 'justifying', provided a theoretical point of integration for the study. The core concept involved the women seeking justification for the options being presented by health care providers, family, and significant others. The concept of justification satisfied the three essential characteristics of a core variable: it recurs frequently in the data; it links the various data together; and it explains much of the variation in the data (Strauss & Corbin, 1990).

Interviewing continued until saturation of categories was achieved. Saturation is the condition where no further examples of characteristic codes are found in the

data and the range of data in the later interviews is accommodated within the existing range of categories (Creswell, 1998).

Memo writing occurred throughout the analysis; a journal of interview experiences that alerted the researcher to gaps in data collection was kept, thus setting the direction for further data collection. For example, the majority of the women that were interviewed were married. Since there is a higher incidence of breast cancer among women who have had no pregnancies, possibly due to an increase in estrogen (Love, 2000), the researcher decided to approach the administrators of several religious communities. The administrators approached the sisters who were appropriate for this study and the women that were interested contacted the researcher. Memos also included methodological issues and concerns, theoretical ideas, analytical insights, and diagrams of relationships. These memos remain grounded in the data by referencing comments and insights to specific quotes by specific women. Memos were coded and analyzed along with the transcribed data at each category and subcategory.

The final step was to return to the existing literature to link the findings to existing theory, and to see how the findings confirm, extend, refine or refute the literature. In this research, findings were compared to existing decision making theories, as well as theories concerning informed consent, patient preferences, risk, coping, quality of life, and stress. Finally the pertinent literature in the substantive area of patient-health care provider and patient-spouse/children communication during adjuvant breast cancer therapy was examined.

Trustworthiness

The value of the research depends on the credibility of the findings. To establish credibility, the researcher returned to the participants with literal transcriptions of their interviews for clarification of content, and expansion of incomplete material. The NUD*IST program allowed the researcher to document and date any changes in a memo that is attached to the participant's transcription. After completing fourteen interviews, the researcher presented the major and minor themes to a group of twenty other women who live with breast cancer, and who attended Reach to Recovery meetings. They offered counter arguments and interpretations of the themes, and suggested atypical cases that could be explored or expanded upon. Their suggestions, along with the gaps that were revealed during the open coding procedure, assisted the researcher in her search for subsequent participants, and maximized the range of information that was collected.

In grounded theory, the researcher must establish confirmability by providing a detailed description of her personal and theoretical biases (Patton, 1990). Prior to beginning this study, in June 2000, the researcher prepared a compilation of all her journal and diary entries she had undertaken during her own experience with breast cancer and subsequent termination of her chemotherapy. She was also interviewed by a colleague, which enabled her to understand the innate desire to provide full and accurate details of a deeply emotional subject. The interview was transcribed, and another colleague analyzed the content (Appendix H). This process was critical because it clarified her beliefs and biases

about the phenomenon of refusing therapies (Patton, 1990). The data were bracketed and set aside while the research process continued. The model that was developed from the data collected for this study is broader and more complex than the analysis that was based on the researcher's interview. The researcher utilized the strategy of memo-writing to further bracket her biases as she listened to the women recount their experiences (Morse, 1991). The women in the study were aware that the researcher had experienced breast cancer and accepted that all discussion concerning her experiences would be minimal and would occur after the interviews were completed.

Human Subject Considerations

With any research involving human subjects, the participants must be safeguarded to ensure an ethical approach to the research process. Absence of intrusive measures, a full description of the research process and expectations, and respect for free choice to participate are essential ethical concerns. The Human Research Ethics Board in the Faculty of Agriculture, Forestry and Human Ecology, evaluated and approved the study in October, 2000.

Participants were adequately informed beforehand about the nature of the study to ensure that they could make an informed choice about their participation. They were also made aware of the measures taken to secure their information. Pseudonyms were used wherever participants were mentioned in the research, and all identifying information that may personally link any individual to the study was removed. As stated previously, the first letter in each participant's name equates to the order in which she was interviewed. The master list linking the

participants' names to their pseudonyms was stored separately in a locked file. The audio-tapes are stored in a locked file and will be erased at the conclusion of the study, as recommended by the ethics committee. Only the researcher and her supervisory committee have access to any identifiable data. Each participant signed a letter of informed consent (see Appendix A2) and was assured of her right to withdraw from the study at any time. No potential health risks were anticipated. Should the participants have become upset or experienced discomfort as a result of participating in the study, referral to an appropriate service was available. No one expressed any discomfort and no referrals were required.

Summary

In this chapter, general aspects of qualitative research, and specific aspects of the grounded theory method were described. The grounded theory method was then applied specifically to determine the decision making process of women who have refused breast cancer therapies. Consideration of trustworthiness including credibility, transferability, dependability and confirmability were addressed. In the next chapter, the analysis of the decision making model of women refusing treatment will be described.

V. RESULTS

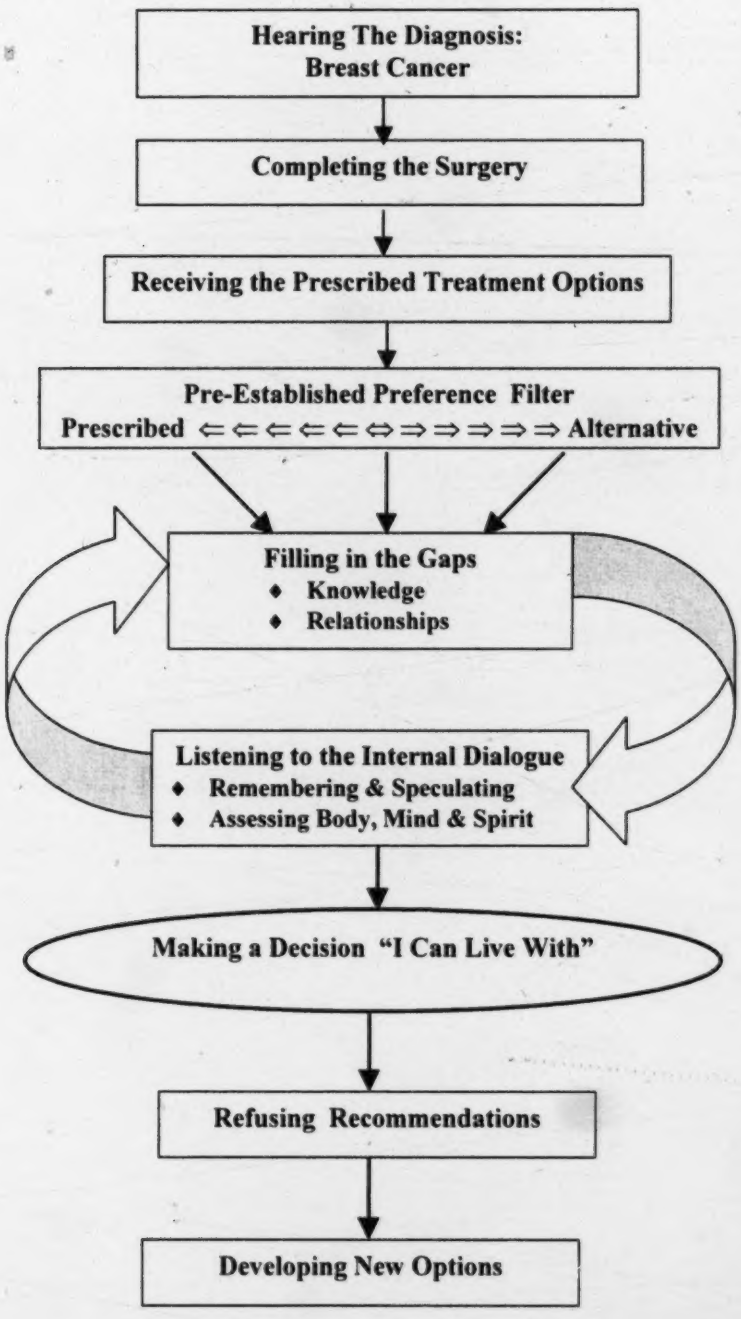
Overview of Chapter

The data analysis is depicted in Figure 2 as a composite picture of the women's journey from the discovery of breast lumps, through their choices concerning prescribed breast cancer therapies, and finally living with their decisions: Model of the Justification Process. All of the women came to the experience of breast cancer with unique family structures, values, and cancer related experiences. Their diagnosis of breast cancer was followed by surgery: either a mastectomy or lumpectomy and the removal of axillary lymph nodes. (Two women had adjuvant therapy prior to their surgery and further choices of therapy.) A team of oncologists determined adjuvant therapies and their recommendations were presented to the women.

The women in this study already established a preference along a continuum between prescribed therapy or alternative therapy. Consequently, their decisions were filtered through their pre-established preference as they searched for additional information. All of the women had medical consultations with an oncologist prior to making their final decisions.

The data analysis chapter is built upon the one core category that is the foundation of the Basic Social Process: "Justifying: Building the Case". This core category describes the theoretical process that the women followed. First the women had to "fill in the gaps" by searching for answers in an attempt to make sense of their situation and justify their decisions. They did this by investigating

Figure 1: Model of the Justification Process


Hearing The Diagnosis:
Breast Cancer
Completing the Surgery
Receiving the Prescribed Treatment Options
Pre-Established Preference Filter
Prescribed ⇐ ⇐ ⇐ ⇐ ⇐ ⇔ ⇒ ⇒ ⇒ ⇒ ⇒ Alternative
Filling in the Gaps
♦ Knowledge
♦ Relationships
Listening to the Internal Dialogue
♦ Remembering & Speculating
♦ Assessing Body, Mind & Spirit
Making a Decision "I Can Live With"
Refusing Recommendations
Developing New Options

current information, and by seeking advice from breast cancer survivors and others. As the women explored their options, they reviewed their findings with health care providers and attempted to get significant others "on board" by justifying to them the decisions they were considering.

Second, throughout this whole process of searching for external answers, the women carried on an internal dialogue to justify their decision to themselves: remembering the cancer experiences of others, speculating on the causes of their breast cancer, and assessing the impact of the treatment options on their body, mind, and spirit. When the hermeneutic process of filling in the gaps and listening to their internal dialogue was completed, the women either refused all prescribed therapies, or they accepted part of the recommendations and refused or modified others. In either case, they developed new options for the treatment of their breast cancer.

Justifying: Building the Case

Critical investigation from a qualitative perspective recognizes that real life is more complex than cause and effect. In grounded theory, the objective is to reduce the complexity of the individual experience into a theoretical process that represents the overall phenomenon of justifying the modification or refusal of therapies, and remains true to the essence of the each woman's experience. Each incident becomes important as an ingredient within a broader concept. The women in this study went through their own theoretical processes of analyzing all the data at their disposal to build a case that would eventually justify their final decisions. At this stage of the study the data are analyzed at an abstract level and

each woman's case is compared with all other cases. Both the researcher and the participants are filling in the gaps.

Filling in the Gaps

At this point in the decision making process, the women had been diagnosed with breast cancer, and they had consulted with their surgeon. All but three of the women had their surgery before they accepted or refused further medical interventions: two women had chemotherapy first and one woman used alternative therapies for six months prior to surgery. Further medical consultations occurred and the women made informed decisions to accept or refuse the prescribed therapies. As the women continued through the decision making process, they identified several limitations in the initial medical consultations. They described the additional resources they consulted while they were exploring the treatment options: reading, libraries, the Internet, and breast cancer survivors. Throughout the decision making process, the women reviewed their options with significant others, who either offered support and insight, or added to the confusion until a compromise could be established.

Limitations of the Initial Information

There are several reasons why women in this study perceived that the initial information that they received did not answer all their questions. Firstly, the women may not have been able to comprehend the information at a time when they were overwhelmed by the diagnosis of breast cancer. When Querida looked at her mammogram, she said that all she could see was "this big white river!"

> And so after I got dressed I said, "You know, can I talk to her (the physician at the Breast Imaging Clinic) again?" So I waited around after

> the clinic was closed. And I waited for quite a long time, and sat in a room with her. Because I just needed to look at it again. I needed to absorb it and say, "Please, just explain to me how this is a cut and dried situation that you are telling me about here! Because this is big deal!" But she was very good, and explained it. And I went out there, not feeling ANY BETTER, but at least a little more informed." (Querida)

During the post-surgery appointment at the cancer clinic, women remembered parts of the appointment vividly, but they could not remain focused for the remainder of the explanation.

> The oncologist was speaking away to me and was saying that we need to get clear margins, we have to go back in again and blah blah blah. And when I looked up and I saw the word mastectomy, and then a box with a check mark in it. And that's how I heard. He was squeaking on the white board right, reek, reek, reek, talking away. (Ellen)

Secondly, when the women ask their surgeons for more information, the surgeons often told the women to wait until their consultation appointment at the cancer clinic to reduce information overload. The women who accepted their surgeons' suggestions and postponed their search for information, assumed that the cancer clinic would provide definitive answers. They were disillusioned when they realized that they were still responsible for making their own decisions.

> You don't know what the right thing is to do. And I certainly went to the Cancer Clinic thinking that they are going to tell me what to do. And they didn't tell me anything. (Audrey)

Thirdly, there were several women who did not trust that the cancer clinic would provide "an unbiased source of information" (Dominica) and they preferred to explore alternative options.

> When I found out that I had breast cancer, I was not given any information. I was not given any, even from my (family) doctor. I was not given any resources other than the next step, "Well you can contact the Cancer Institute." Right, like, "Wait a minute. I don't want to go there. I mean I want to learn about my disease before I do anything!" (Dominica)

Pamela and Odette asked their surgeons for information, and they were informed of all their treatment options and given Dr. Susan Love's Breast Book (Love, 2000). They appreciated this information, and the fact that the oncologists got together as a group and collectively determined the best treatment for their individual situations. However, they still wanted to expand their search concerning treatment options beyond the therapies prescribed at their local cancer institute.

Whether the women were given information immediately after their diagnosis, or waited until after their consultation with the oncologists, they all recognized that they required further sources of information before they could justify their final decisions.

Investigating the Current Information

The printed word was considered the primary source of current information for the women in this study. They consulted reading material (books, magazines, journals and pamphlets that they collected from retailers) (94%), other women who had experienced breast cancer (88%), second opinions from health care providers (88%), libraries (50%), and the Internet (50%), and videos (1%). Since the women usually referred to the "reading" that they did to inform themselves, this section will begin with the general category of reading, and conclude with a separate section that focuses specifically on the significance of utilizing the library and the Internet.

Reading

The book most frequently quoted by the women in this study was Dr. Susan Love's Breast Book, which has been in publication since 1990; the third edition was published in 2000. The New York Times called this book, "The bible for women with breast cancer". Women took this book with them to their medical appointments when they had questions about their prescribed therapies.

> And I guess what got me from that particular book was, she [Dr. Love] said "Tamoxifen has proven itself very successful for reducing breast cancer in the other breast. But it is over prescribed. Every physician prescribes it to every woman who has breast cancer and yet, they know it only helps 20% of the women who have breast cancer. But they don't know who the 20% are. So, therefore, 80% of the women who are taking it don't need it. And you are putting another chemical into your system. Something else for your body to deal with." And I felt there's a lot of merit to that. (Audrey)

Audrey argued that, according to all the charts in Dr. Love's book, she should not be taking tamoxifen.

> I read all of the charts that if you were premenopausal, if you were this age, if your tumor was this size, you won't take tamoxifen. So here I was, having read all of this, and they (the oncologists) are saying, "No you have to take it." And I am saying, "But I am premenopausal, I am all of this, you know." They said, "Well, your risk is just too high."(Audrey)

This conflicting information created a huge dilemma for the women because they recognized that there were no absolute answers and they had to decide if the information they were reading was accurate for their individual situation.

Two women attained their copies of Love's book from their surgeons. They began referring to the specific sections in Love's book as soon as their surgeons told them they would need a lumpectomy.

> Whenever I required clarification, I would fill in the spaces [areas that needed clarification] with stuff from the book. And then it raised another

> question and I would go further into it. I just wanted to be informed. (Pamela)

> The surgeon's comment was, "This might help you get an understanding." I recommended the book to my friend because I found it very helpful because it is so clear. She [Love] doesn't mess around. (Odette)

Not all the women consider every word in Love's book to be the gospel truth. Querida was initially concerned because Dr. Love's recommendations concerning tram flap reconstructive surgery because she states that the saline implants may not last as long. While Querida wished she had read Love's book before she had a saline implant, she disregarded Love's suggestion because she knows women whose silicone implants are still intact after ten years. Querida actually used quotes from Love's book when her husband's divorce lawyer required justification for additional resources after her surgery.

The women were motivated to search for information when their oncologists altered the original course of therapies, especially when there had been no new factors introduced to justify the change.

> They said, "We've decided to give you 10 more boosters." So I did some reading on that and found out that that was unusual. That 8 was normally the maximum. And that 2 of the 3 oncologists at the cancer institute were no longer giving boosters at all. They had found that the percentage of women that it helped wasn't that large. So, I asked my oncologist "Why?" And she said "We're just not comfortable with those unclear margins." (Audrey)

Since Audrey had taken the time to find out that additional boosters were unusual, she was offended when the oncologist said he considered her information to be invalid.

Every woman in the study, except Helga, claimed to have done a massive amount of reading, to the point of being saturated with information. The

oncologists provided pamphlets, and friends who had experienced breast cancer offered their earmarked books.

> Of course, as soon as people know that you have it, it's like everybody you know knows somebody whose had breast cancer, and "Have you read this." And "Have you thought about this". And it's like, "Okay, I'm on information overload. I've got the information I need." You know you can read so much, and then it's like you are reading the same thing over and over again. You are just hearing it from someone else's perspective. (Bernice)

Not all suggested reading material was appreciated, and unsolicited literature on healing or self-help books became overwhelming for some of the women.

> I told my mother that I have been on overload for a long time now. And I have recognized that I cannot read another 'blessed' thing on improving my quality of life. I can't because I will just implode. (Faith)

Well meaning friends and family supplied books on diet and alternative therapies. One woman had a list of about 30-40 books that she had read, and she was having trouble deciphering all the alternative therapies.

> There are so many conflicting areas. I mean it was just like bombardment. I mean it was just like, I mean I read, I read all these books, and I did research until it was my husband saying, "You've done enough! You can't." I mean, I had to find out what I had to do! Because once you refuse treatment at the Cancer Institute, they don't want to see you! And you are out there in the ocean without a paddle. (Irene)

Six women started searching through their books on holistic medicine as soon as they learned that the mammogram was "looking weird". Michele referred to her books by the holistic doctor, Deepak Chopra, who she said does not advocate chemotherapy for all breast cancer because often the cells are slow growing and chemotherapy only kills fast growing cells.

> So it will kill everything else, it won't kill the breast cancer cells. He states in there the cancers that specifically work well with chemotherapy. Like

> there are some. Like he said child leukemia and prostate, or testicular, not prostate in particular. And then there were a couple of others. But then it goes on to say that the breast cancer isn't one of them, because the breast cancer cells are slow growing. I am pretty sure it was mentioned in there. And I have also seen it in a couple of other books. (Michele)

Michele said that the amount of reading that she and her husband have done in the last six months was "huge". Most of their information came from books Michele's sister had used prior to her death from metastasized breast cancer, and articles from the Alternative Medicine Research Clinic. Every time they read about new advances or diagnostic tests, they would take the articles to her family doctor to see what he could "wangle up" for her. Since her surgery, she read articles that would have altered her original decisions concerning biopsies and lymph node removal.

> The more reading that we've done too, you know, I would have never got the lymph node surgery. I actually probably never would have got the initial needle location biopsy done. Just basically because now the reading that I have done is saying that the DCIS (ductal carcinoma in situ) is usually a benign cancer, and it should be left alone. And that the more you play with it, the more likelihood that it can go into something else. (Michele)

Popular magazines such as Time, Reader's Digest, Chatelaine, Oprah, and Rosie have breast cancer stories advertised on their covers, so the women purchase the magazines, or their friends give them to the women. Women also turned to books on subjects involving women's lived experiences of surviving breast cancer, or dying with dignity.

> The March publication of the Reader's Digest came out. And on the very front of the cover was a picture of an oriental lady, and it said on the cover, "How I Survived Breast Cancer". …It was quite an interesting story, and she wrote it very plain English, just how it was. (Pamela)

> I read that book by Aniko Galamas if I really get down with a bad feeling. But even so, a lot of them had things that went wrong with them and they are still fine. But the one who had it worse was Judy Reed, who did the quilts. And I think she's still vital. And I think, how could she be! She's already bought presents, little crystals for her kids, right up until they are twenty-five. (Jocelyn)

Roseanne recommended the book "Grace and Grit" to other women who have breast cancer because she thinks it is so honest. The book is not just about therapies, it's about coping, and it represents the healing power of reading.

> He's written this book because he married a woman and within 10 days of their marriage, she was diagnosed with serious breast cancer. And went through the whole shmear. And on the front of the book is a picture of the two of them together when she has lost all of her hair. And of course, he has had his head shaved for her. So, here are these two bald people on the front of the book. And it is a wonderful story because it really is from the caregiver's point of view as well! Because they both kept diaries. (Roseanne)

Investigating in Libraries and Surfing the Internet

The local libraries proved to be a tremendous resource for half of the women in this study. They felt that the library books helped them to decipher their lab reports, make sense of the statistics regarding the risks and benefits of different treatment options, and clarify evolving treatment dilemmas. Determining the performance of drugs regimes and radiation was part of justifying the success rates of prescribed therapies.

> The general information was valid. You know. Certainly the chemo drugs have been around long enough that they know the side effects, they know how they perform, they know to what degree they are going to work. And, I looked at that saying, this is what I have to be prepared to do if I am going to do this. And I felt better going into it knowing than not knowing. (Audrey)

Every time the women received conflicting data, they would find themselves returning to the library for more books. Jocelyn and Pamela used the library that was run by volunteers at the cancer clinic, and Geneva's surgeon took her to the research library at the cancer clinic.

Liz made a comment that the information she obtained from the public library was from books, not from articles. However, Kim, Bernice, Geneva, and Michele mentioned returning to the original articles or to scientific journals or reputable sources. Kim refers to herself as a scientist. She read the protocol for the drug trial in which she took part and challenged the oncologists when they were going to add tamoxifen, because it was not in the original protocol.

> Isn't that just like another variable? I didn't like those numbers that were coming off the page. So, he couldn't convince me that way. Then I started to find out about tamoxifen. What I was able to ascertain, from all the literature that I read, and I went back to the original sources. Not someone's interpretation of something. It appeared to me that there was still a lot of doubt whether that worked in pre-menopausal women. (Kim)

She also researched natural substitutes for tamoxifen that claim to reduce the chances of a recurrence. These women are university graduates who are knowledgeable about research and who know where to search for current data sources. The librarians guided these women to appropriate literature and helped them gain access to web sites at the library.

Nine of the women in this study stated that they used the Internet to learn about the prescribed therapies, alternative therapies, and drugs that had been recommended or advertised.

> I finally sort of got an understanding about what different types of cancer there were, and what intraductal was. I went and looked at all this stuff on the Internet, and went to, you know, reputable sites. And when I was

> looking at the diagnostics, different grades or levels of cancer, or whatever. I would go in and try to get an understanding of that, to make sure that I wasn't confused about what I actually had. (Querida)

> I went on the Internet between my fourth and fifth treatment and found out that Adriamycin can lead to fatal congestive heart failure. And that everything I was experiencing was because of Adriamycin. And nobody had told me this. (Faith)

When Pamela started having symptoms related to the tamoxifen, she and her husband found information on the Internet that convinced them that tamoxifen was not appropriate for her. Pamela "bugged" her oncologist after she read about another kind of estrogen blocking therapy that was replacing tamoxifen. The oncologist told Pamela that the drug was not appropriate for her, and the only drug they recommended for her was tamoxifen. Pamela was not swayed from her resolve and she said, "Well it ain't happening. That's out!" and she terminated her tamoxifen.

The web sites not only provided answers to questions, they provided a link to other women who had experienced breast cancer. Family members sent files to their mother, sister, or aunt, and suggested valuable sites. Ellen used one particular site on the Internet that focused on breast cancer and linked her to individuals all over the world.

> I have been on this breast cancer list now for just about the whole duration, ever since my diagnosis. And there are over 700 members all over the world, patient advocates, oncologists, nurses, lawyers, everything. Excellent site. You can throw out any question and you will get an answer. Whatever is just coming on in the media now, I've heard about it already. Evista, Femerol, all of it. (Ellen)

Kim talked about a web site that's trying to connect all the different sites that you can go to for alternative medicine.

However, not everyone considers the Internet a reputable source of information. Some health care providers discouraged use of the Internet as a source of accurate information.

> The first thing the surgeon said before I went to the Cancer Clinic, he said, "Don't go on the Internet and read all that stuff. There is too much misinformation on the Internet, so go elsewhere, first. (Audrey)

Roseanne, Liz and Odette said that they did not have access to the Internet when they were diagnosed. They were also not sure how much of the information was "good stuff" and what was "junk". Roseanne said, "When you are in that kind of situation, you really want stuff that you can rely on". They suggested that appropriate web sites could be recommended at the consultation appointment.

Several women mentioned phoning 1-888 numbers, usually the Canadian Cancer Society, just so that they could "talk" to someone who was prepared to answer their questions and send some information. Unfortunately, Roseanne, Odette and Michele found that the information that they received from the Canadian Cancer Society was not pertinent to their situations and they went elsewhere for more personal contact.

Seeking Support from Those Who Can Empathise

The women in this study were in agreement that "You have a *need* to speak to other women who have been there." The amount of information is overwhelming and "talking to other women who have been there stops the spinning." Querida used her divorce as an analogy for how women need to approach others to help them find information.

> When I thought, I need information on getting a divorce, I would talk to somebody who has been through it. I want to know the whole truth. And I

> don't know where you go to get information. And it's the same thing. So you have to really look around. Because this is your life, you want to make the right choices. You want to make ones that you can live with that are comfortable. You don't want to have regrets. (Querida)

The breast cancer information involves "a whole new language", that is often housed in a location that is not easily understood by everyone. The participants identified three ways that they located women who had first hand knowledge of breast cancer: the volunteer organization called Reach to Recovery, support groups organized through the psychology department at the cancer institute, and through word of mouth, where someone knows someone else who also had breast cancer.

There was a consensus that women should contact breast cancer survivors for support and so that "you realize that you do make it." [The term 'survivor' was not appreciated by several of the women in this study who do not consider themselves to be at war. Therefore, the word 'survivor' will be used sparingly.] The Canadian Cancer Society operates a support service called "Reach to Recovery" that provides personal visits and groups support meetings for people living with breast cancer. (Canadian Cancer Society, 2001) The volunteers are specifically trained women who are considered to be "breast cancer survivors". During the visits, the volunteers are not allowed to give medical opinions or advice, and personal comparisons are not supposed to be given. Within these parameters, Reach to Recovery volunteers (1) help women come to terms with their diagnosis of breast cancer, and (2) discuss the feelings and anxieties that may be experienced by women who are told they have to have surgery and/or chemotherapy/radiotherapy for their breast cancer.

With approval from the patient's surgeon or doctor, a volunteer from the Reach to Recovery program visits the woman at the pre-admitting appointment for the surgery. They provide each woman with a temporary breast form and useful printed information. The volunteer may also answer other non-medical questions such as where a permanent prosthesis can be purchased. The women are informed about related community resources. This initial visit takes about fifteen minutes and the same woman usually makes a follow-up visit or phone call, inviting the woman to a Reach to Recovery group meeting in the community.

> I had a visit at the hospital from a Reach to Recovery lady. She told me what to kind of expect a little bit. And that I should do exercises. Later she phoned me and said, "Pamela, you should come to a meeting! Come to a meeting before your surgery!" Because there is all kinds of information. (Pamela)

Nine of the women expressed extreme gratitude for the time these volunteers dedicated in order to met with them individually at the hospital or at their home.

> I was so grateful for them, you know that that was something they had chosen to do, and are there. It's just a powerful support system. (Bernice)

> They came to visit me when I went for my orientation at the hospital. A Reach for Recovery woman brought me a little bag, and my temporary prosthesis, talked to me, told about the Reach for Recovery. Told me about where the different prosthesis places were when I had my surgery and when I was ready to go ahead with that. Or if you are going to have plastic surgery, they explain the choices. (Carolyn)

These women mentioned several times that when they attended the meetings, they were reminded that there are other women who have gone through much more aggressive breast cancer and still survived.

> They talk and they are so upbeat, it kind of makes you feel positive. Makes you feel like, okay been there, done that. It's over and done with and you see the new ones coming in that are in progress and you think, "I don't want to be them anymore." (Carolyn)

Women continued to attend the Reach to Recovery meetings to support other women who were "joining the ranks".

> I've run across all sorts of women, and the repetitive message I am hearing is, you know, I'm a nine year survivor, I'm an 18 year survivor, I'm a 25 year survivor. So, yeah. It's nice to know I have an opportunity to grow old! Yeah. It puts a new perspective on things. (Faith).

Women make friendships that last a lifetime because they have encouraged each other through a time that is life changing.

> The lady dropped in from Reach to Recovery who has been a very good friend ever since. That was May --, 1995. She invited me to come to one of the meetings and meet other people in my same situation and people that had been survivors of 30 years or so. It certainly wasn't the end of the world, and there are many things that could be done and interesting people to meet at these meetings. (Geneva)

Three of the participants are now volunteers with Reach to Recovery. Querida said she told the group about her experience concerning her saline implant because no one had been able to prepare her for the logistics of the whole procedure: "I want to share that information with people because there's lots of other people that are in the same boat." Irene brought out her memory album and described her first Reach to Recovery meeting because she thought it was so important to her survival. Since she didn't have anyone from Reach to Recovery visit her in the hospital, she thought it was important to become a volunteer herself.

> The need for that is so important. To have somebody come and see you and then you have that bag with all the information in that you can read or not. At least you can inform yourself if you want. I am never any longer than 15 minutes. But in 15 minutes I can put them at ease. I can lessen their anxiety. They can see that I have been there. And I am here, today. (Irene)

However, she reiterated several times that she has to be discrete about informing women about complementary medicine because one of the other volunteers was told she was no longer welcome because she didn't follow the rules. The Reach to Recovery volunteers are instructed to offer comfort and some help in how to begin making informed decisions (Canadian Cancer Society, 2001).

> I recommend books to read. But I can't tell them anything. I mean, you can't. Actually one little gal would really tell the girls that were going in to have surgery, to ask your doctor questions and to inform yourself. And so the patients started asking so many questions that the doctors wouldn't let her come there anymore. So you see, the doctors don't have time to answer questions. Not too many, right? (Irene)

The face-to-face meetings are structured to ensure consistency in the information. The meetings are sponsored by the Canadian Cancer Society and there are guidelines concerning the formal discussion. However, there are no restrictions on the informal sharing that occurs.

> "Ladies there will fill you in on what you need to know." Which was really good because they did. One girl told me, she said "Before you start radiation, make sure you call me, because the stuff they tell you, is not good. We will give you the insight on how to treat the radiation system." (Pamela)

Not everyone was impressed with this informal volunteering of information. Five of the women in this study found the hospital visit intrusive and the group meetings depressing at a time when they were very vulnerable. Jocelyn originally decided to have a mastectomy and felt confused and frustrated when the volunteer told her she didn't have to lose her whole breast.

> The survival group had a person come and see me in the hospital. … I went with her (and had a lumpectomy). I think I would be far better if I hadn't of had that visit. Suddenly I was floating again. I had gone there, I am going to have the operation next day. I thought to myself, I would have a mastectomy, have it over and done with, without any lymph nodes

> removed, okay! So, the mere fact that I had all this complicated, what I shouldn't do, and what I could do. Different options and why other people haven't done this and all kinds of things. It totally threw my mind. That was a bad thing. (Jocelyn)

Roseanne felt "insignificant and neglected" when her volunteer forgot the hospital visit. Her attitude did not change when she went to a Reach to Recovery group meeting three weeks later.

> I didn't belong there at all. I really felt as though I simply became somebody for all the people that were there to tell their story to. And I wasn't one bit interested in listening to other people's stories. I mean, I have done that all my life [she was a nurse] and I just drew the line and said, "I don't belong here at all." (Roseanne)

Other women shared their resentment concerning the disagreeable subject matter that was presented at the meetings. One woman said she felt that there was a "conflict of principles."

> I went to this lecture and this woman talked about everybody's deformities. When I came home, I went around and looked in the mirror and I felt deformed. I had never felt deformed before! I never even thought of it! Then they had a mother, a father, a sister, a brother, from different families all sitting there. And, how they all felt when their sister or whoever got breast cancer, okay. That was the most depressing thing I have ever seen! It was almost as if they had brought everybody in to depress them! (Jocelyn)

Reach to Recovery's mandate is to provide volunteers who have been carefully trained to provide advice and reassurance. There are similar support groups that struggle with the sensitive balance of determining the needs of the women who have breast cancer and the limitations of a volunteer group. Essentially, volunteers are careful to state that personal information is related to their individual situation and each woman has to make her own decisions.

There are also smaller support groups that are organized and facilitated by psychologists at the cancer institutes. They typically meet once a week for six to ten weeks. The women reported mixed responses when they shared their thoughts about refusing prescribed therapies.

> I brought this to them (her decision to refuse chemotherapy and radiation), and said how I felt and of course they listened. And there were 8 of us in that particular circle. Some of them were just so afraid for me. Just so afraid, you know, because, "You can't, you have to do this Bernice. You have to do everything to save yourself. And I said, "I am, I'm just doing it differently." And, I really appreciated, the openness that was there. (Bernice)

> When I was first diagnosed, I called one of my sister's support group ladies, and talked to them. But I find, if you talk to people that have only done the chemo and radiation treatments, they don't understand what you are doing. They don't really think you are doing enough to save yourself! They sit around, they talk about their disease. They cry. You know, the woe-is–me thing. And I am going, "Yeah, woe-is-me, but, I can also do something about it." (Michele)

Serendipitous meetings are mentioned frequently by the women in this study. Women who are living with breast cancer come into their lives and an instant bond is formed.

> Get this. I was waiting to meet a friend for lunch, she's (stranger who became a fellow confidant) sitting at this other table. We start to talk about the sunshine. She says, "Yeah. It's really important to me." I said, "Me too." She said, "About a year ago I didn't have any hair so, just even the heat." I started to laugh, and I said, "Well 6 months ago I didn't have any hair either." So here we were, waiting for different people, and we just entered into this conversation. And so we swapped phone numbers and things. (Faith)

The women talk about the books they had shared, the camaraderie during the lonely times, the enthusiasm when their energy returned and the bond that emerged during the evolution of their friendship.

> I think it's interesting the whole plus side to all this are all the interesting women that I have met. And even through my emotional shift. And I think I am a stronger person for it. (Ellen)

As well as meeting new friends, the women contacted individuals who they knew had lived through the cancer experience, men and women. They were especially interested in individuals who had chosen not to have chemotherapy or radiation.

> I spoke to, three people who had chosen, one actually was not breast cancer, it was actually my investment advisor, and he had chosen, and he had said to me, what his experience was. And then, the one that was the closest to my own experience was a friend who, we went to school together, and she is a minister and she had chosen clear thought and visualization as her healing. (Bernice)

They contacted other women who had lived through the cancer experience: women they remembered from their husband's Christmas parties, or former acquaintances from their local curling club or church. The women realized that they all have different stories and ultimately, they all had to make their own choices.

Reviewing Options With Others

When the search for answers reached this point, the women were often overloaded with information and needed an objective viewpoint. The decision is analogous to an eye appointment, where the patient is trying to discern which lens gives them the clearest vision. Which is better, this way, or this way? Each information source is like a different lens that makes the image clearer or distorts the vision in a different direction. Finally, the picture comes into focus and you are left with the clearest vision possible. The final lenses are chosen, your decision is made and you look ahead and see the results from your altered

perspective. This section of the study describes how women approached others to review the prescribed therapies from their unique perspectives. They consulted with health care specialists, respected health care providers, and family members.

Health Care Specialists

In addition to the prescribed therapies, there are weekly reports on the latest findings or changes in the treatment for breast cancer that further complicate the options. It is not unusual for a woman to seek the advice of another oncologist, or the plastic surgeon who would be responsible for her breast reconstruction, or an alternative medicine practitioner who may provide alternative or complementary therapies. The specialists take the time to interpret the medical details and explain the risks/benefits of the prescribed therapies once again.

Many women stated that during their initial consultation, their surgeons did not suggest that they go to the cancer institute until their consultation appointment following their surgery. However, five of the women chose to make an appointment at the cancer institute on their own accord, prior to surgery. Querida's surgeon told her she needed a mastectomy and he had an opening within the week. Since the surgeon did not share her belief that a breast was important, saying it was "just a mound", she did not think his information was valid. Instead she asked for the phone number of the cancer institute and made an appointment with the oncologist.

> I went to the Cancer Clinic too, and talked to them, and I got sort of a second opinion. I talked to an oncologist and they looked at my mammogram and gave their advice, and recommended that the mastectomy was the best thing. And I just thought, "Okay." (Querida)

The women appreciated the oncologist's opinion based on an investment of time and caring that resulted in a deeper level of trust and communication.

> I think that there was an investment, the radiation oncologist kind of entered the journey a little bit more. The surgeon was very stand offish. And I think that that was the difference. There was somebody who, you know, she could tap into what I was saying and continue the conversation. He just gave data. He never really connected with the sentence that I would say. He would just let that sentence go, and then add another sentence that was not necessarily relevant. (Odette)

One woman was so impressed with her oncologist's persistence, that she was persuaded to start taking tamoxifen after initially refusing the drug.

> The medical oncologist spent 40 minutes one day, trying to convince me that it still wasn't too late to take chemo. And I said "No, I am not taking chemo." There is no question about it. I will not take it. So then she said, I had better take tamoxifen. And I had also read about 4 books on tamoxifen and I was just totally against it. And she argued and argued and argued. And I guess finally what convinced me to take it was the fact that she spent over an hour arguing with me on the benefits of taking it, versus all the side effects of it. And I thought, either she really thought I should take this, or she wouldn't have spent this amount of time, she would have said fine, this is your decision, we'll leave it at that and left. Because she had other patients waiting and you know, 40 minutes, an hour, was a lot. (Audrey)

Establishing a rapport with a physician leaves the door open for the woman to return. Querida returned to the oncologist after attending a Reach to Recovery meeting where the women were extolling the value of radiating the lymph nodes versus surgical removal of the nodes.

> When I talked to the oncologist after the pathology on the mastectomy that showed the spots, I said, "Can't you just radiate my lymph nodes? And she said, "It wouldn't do any good." And yet I have talked to other people who had radiation treatment on their lymph nodes. There's still sort of all kinds of gray areas I guess, so it was good to get her opinion. (Querida)

Prior to the mastectomy and lymph node removal, Querida decided she should consult with the plastic surgeon that would do her reconstruction.

> He told me that if I had radiation, then that would sort of toughen the skin, and it wouldn't stretch and all that sort of stuff. So having radiation was, you know, a sort of a decision that I had to make.

Inevitably, it remained her responsibility to choose whether she would accept or refuse radiation. She felt reassured by her search for clarification concerning her treatment options, and confident that her breast reconstruction would leave her feeling balanced again.

All of the participants went to the scheduled consultation appointments with their oncologists to hear what they had to say, even if they had decided prior to the appointment that in all likelihood they would refuse. They maintained that they wanted to get all the information in case they missed something. For eight of the women, the initial consultation with their oncologist was their first and their last: five refused all prescribed therapies, and three refused chemotherapy and radiation and accepted the tamoxifen.

> The decisions were being made along the way. On the one hand with me pretty firmly opinionated. But on the other hand saying, I am open to all information. I am willing to have my mind changed. If they can show me better information than I have already found, or justify this in some way that I don't know about, then I better be ready to listen. So I was going with that approach. I was also armed with statistics and risk benefits and all those types of things, to discuss with them. By the time I went to him (the oncologist), there was still some question in my mind about tamoxifen. And so, probably I was thinking I needed to know a little bit more about that. (Liz refused all therapies.)

The women acknowledged that "Western medicine is not where it is for nothing." They accepted the surgical removal of the malignant tumor and did not want to remove themselves from the "orthodox route." The women were

concerned that they may need to return to their health care providers if their breast cancer returns. If communication and trust were established during the decision to refuse prescribed therapies, the women felt reassured that they could return in the future, if that became necessary.

> Obviously, if I get into more trouble, along the way, I may need chemical support of some kind. Whether it's chemo or not. But you know, I could get pretty sick. So I need to have these contacts. And I need to have good relationships. (Liz)

Positive relationships are built on trust and communication. The next section illustrates how the women attained a second opinion from health care providers they respected.

Respected Health Care Relationships

Reviewing the options often means seeking a second opinion. As Dr. Love (2000) states, "the treatment of breast cancer is far from straight-forward". Seeking a second opinion often resulted in a different option from the prescribed therapy. Since the women had established a rapport with the second health care providers, they placed their trust in the second opinions. Insecurity did arise for some women who came to the realization that there would never be "one right answer". Objective truth is illusive and there does not appear to be one right way to treat breast cancer.

Six of the women commented on their psychologists' ability to relieve their fears and shed some light on the interconnection between physiological and psychological symptoms. They found that the nurse triage line and/or their physicians often labeled the women's symptoms as anxiety, when in fact they had

legitimate complications. This diminished their trust in the physician and/or nurse triage line and strengthened their relationship with the psychologists.

> So by the time I went for the fifth chemo treatment, I was pretty sure it was going to be my last one. Because it was actually the psychologist who said, "You have an option here Faith, just because they said you need to do six, you don't need to do six. Six is an arbitrary number. It's perhaps a summary of different research findings, and so they just decide, based on the numbers that this is good enough." And I said, "You're right!" Like, I'd gotten so into this, "You have to do exactly what you are told." And I was so grateful to her for reminding me that I have choice here. You start to question whether or not you're really seeing things, or you are just imagining things! I found I really questioned myself and I get so upset with myself! I had done a number of years of psychotherapy, and had learned about my body, and listened to it. And here I was listening to it, but then I would be told that I was out to lunch! The only person within that institution that supported me, it seemed, was the psychologist. (Faith)

When trust and communication were established with a health care provider, the women said that they felt as if they were "seeking permission" to make the decision that they were feeling at a "gut level".

> I said, "Well I don't know what to do." And he said "Well, what is your gut feeling?" And I said, "My gut feeling is I don't want any more surgery! After all this heart surgery." And he was very good. He came and watched my heart surgery. He came and saw me after the heart surgery and said, "Do you think you can go through this yet." So he was very conscious of what I had been through. And he said, "What is your gut feeling?" I said, "My gut feeling is no more surgery." And he said, "Okay, go with that. Your mental attitude has a lot to do with your healing. If you feel comfortable, and if you feel good about saying 'No more surgery', go with that and go with what you think is your gut feeling." Well, he said, "You'll probably come out of this the same as if you have all this other stuff done." And he said, "To put you back under again for the third time in two months, you run risks there too." So, I went back to the oncologists and told them "No, I wasn't having any more surgery, I would not have it excised, I would not have my breast removed." (Audrey also refused chemotherapy at that same appointment.)

The older women experienced a filtering of information by their surgeons. The two oldest women relied on their surgeons and family doctors that had

consulted one another and came to the conclusion that radiation therapy was not necessary for their patients. Since they had established a trusting relationship with their physicians, both women agreed with their suggestions to refuse radiation.

> I went to see the surgeon. He said, "By the way they (lymph nodes) were very clean. I don't think you need to have any radiation, but if you want to, sometimes people feel better about it." I said, "I don't think I really want it." (Geneva)

> He (surgeon) got together with my doctor and said, "We're not the experts, but this is what we think." He thought the amount of radiation they wanted to give me, the way my insides are sensitive, it would probably have done more harm than good. And so I took it from there. Lord knows, that's it. My mind was made up. (Helga)

Both of these women also accepted their surgeons' suggestions to take tamoxifen. However, Helga was concerned about the side effects of tamoxifen and was going to consult her surgeon about terminating this therapy.

One surgeon actually screened the oncologist for his patient because he was aware of the woman's pre-established preference for alternative therapies.

> When it came time to refer me to an oncologist, he said, "Well, I'm not going to send you to Dr. So and So who is a sort of high profile leading breast expert in the community here. I don't think you and he would get along too well. But I know another guy who is really good and I think you will be just fine with him." And again, that was a good choice. (Liz)

Several women in this study talked about the moment when they realized that they needed a recap of the prescribed therapies from the perspective of a physician who had lived through a cancer experience.

> I did ask to see one of the other physicians as well, because it was somebody that I knew! And both of these women doctors have both had mastectomies done! I know, and I think one of them has had bilateral done. So they are coming from a different place, they are coming from the experience! (Roseanne)

> I asked them (the oncologists) if I could go back to my GP because I was comfortable with her. She was on the same wavelength as me. She went through cancer (uterine) herself. And so she went the route and she said, "Everybody to their own." And she didn't push anything. (Carolyn)

Bernice actually received an unsolicited second opinion from the head of the oncology department. His explanation was in marked contrast to that of the first oncologist: the information was not different, it was presented differently.

> She (oncologist) said that I could be cured if I began this (chemotherapy) right away. And I was just saying to her, I was just not going to make the decision that day. And, at one point, the oncologist looked at me, and she said, "ARE YOU CRAZY?" And then she turned from me and she said, to my husband and my daughter, as if I didn't understand, "Does she understand what I am saying?" And of course, my daughter is a psychologist, and she said, "Oh YES! She understands very well". And then she just said, "Talk to my Mother, don't talk to me." … So it was good to be with this other oncologist. And to just have his calm, and get the information again, hear it in a different frame of mind. He knew that I had taken it all in, and got a different perspective. (Bernice)

Eight women in this study had placed their confidence in alternative medicine prior to their diagnosis. Therefore, consulting with an alternative therapist after their diagnosis of breast cancer was a natural response.

> At the time that I was diagnosed, my family doctor was a holistic practitioner, as well as a licensed GP. And I had been seeing her for some years, because of all this other health crap, so I was already pretty well steeped in the idea of holistic stuff. And she doesn't mess around, you know. When there was something like breast cancer possible, she just said, "Off you go to the surgeon. Off you go to wherever." Then I was continuing to see her and she was helping to sort of coach and helping mostly listening to me as I made my decisions. (Liz)

> I wanted to see what they (oncologists) would say and how they would say it. Right. And then I wanted to talk to my naturopath too. I had pretty much always dabbled in herbal medicine from my early 20's. Right, and had always gone to a doctor only to get a diagnosis. And then I would come home and treat myself! So when I got the diagnosis, I wanted to also start the homeopathic medicine in full swing. And we (husband) had already seen this naturopath…. The first surgeon laughed at natural medicine. Which to me was an assault against my belief system. And he

> was telling me that I was a fool to even believe in that type of medicine. (Dominica)

The women chose physicians who they thought would listen, and then mentor them through the decision making process and respect their belief in "natural medicine".

All of the women who consulted alternative medicine practitioners stated that they were never told specifically that they should not accept chemotherapy and/or radiation therapy. Instead the practitioners allowed the women to explain their pre-established preferences and then provided information that documented the risks associated with adjuvant therapies.

> The holistic clinic was actually directly connected to the cancer hospital. These are medical doctors, who just believe there is more to healing than the chemicals and the pills that they give. And they have fought for this! It just affirmed that's where I belong. …They didn't go and say, do not take the chemo and do not take the radiation. They were saying, "Look at all other options." That that was such an invasive process. "Here is the information around chemotherapy, here's some of the negative sides. Now, with that information, you must make your own decision." (Bernice)

> The Alternative Research Centre said if I decided to do the chemo, that they would be able to help me as far as the side effects. Because there are things that you can take so that you don't suffer any of the side effects and that can make it a lot easier. (Michele)

Three women asked their alternative practitioners to prescribe alternative medicine to minimize the effects of the prescribed therapy that they accepted.

> I went down to the States and I spent as much time as I could down there. I would go down, I'd come back and I would get my treatment and then go back down. So, I mean, I would come up, have the treatment, be sick for 5 days, and then get on a plane and go back. So I spent almost three months down there, working with a Qui Gong master. And that was freaky. (Kim)

Health food stores and pharmacists were also consulted as women prepared to cope with the side effects of the adjuvant therapies.

> Up to the time I saw the oncologist, I was going to go with the radiation, this was what I was going to take (she produced a list of medication/herbs that she had planned to take during her radiation treatments). Because I had been to the health store and I found what I should be on. Well then I mean, that experience in the room. (She refused radiation when she went into the radiation room). …I went to the pharmacist and he gave me the book (Cancer Battle Plan), which is so incredible. Anyway, so it's cancer therapy and they have actually done research and studies on that. That has knocked out cancer cells in the body. (Irene)

The women returned to the alternative practitioners after they left the oncologists, because they felt personally responsible for maintaining their own health care.

> The lump was already there under my arm. And nothing showed up there as far as something being cancerous, or you know, harmful or whatever. So I thought, well I'll go back there and basically what came out of it was that, long talks with both of them (oncologist and alternative therapist), and we decided that we (husband) are going to go with boosting my immune system. And working with my body as a whole, rather than trying to have somebody else cure me. (Michele)

> I went to a woman who does massage therapy and iridology for stuff. And then I was diagnosed and I went in to see her again and I sat down with her and I said, "You know, I have been diagnosed with breast cancer. So I am just wondering, do you have anything that can help me?" Well right there she jumped right in, and pulled out her book, and brought all this stuff, you know. Did all this stuff. But I just, I don't know, I just felt that it was slow! I just had a feeling that it (the herbs) was going to take too long, and I didn't want to take the risk. I decided to have the lumpectomy and then I continued with the alternative medicine after I refused radiation therapy. (Querida)

The decision to use alternative medicine as a complementary therapy, or to rely on it exclusively and exclude traditional treatment, is a highly personal decision. During the whole process, the women's families were consulted to a greater or lesser degree. The final review involves the family members, and how they influenced the women's decisions.

Getting the Family On Board

It is important to acknowledge that the ramifications of breast cancer extend beyond the women and affect their families. Communication with family members was considered a crucial element in the decision making process for all of the women. The most significant relationships for the majority of the women were with their husbands (75%) and their children (80%), as indicated by the number of text units coded in that category (588 and 514 text units respectively) (see Table 9). Each text unit consisted of two lines that were coded directly from the original transcripts to the corresponding category. The categories included positive and negative statements.

All of the women mentioned that extended family members were more involved with providing information and support rather than influencing the women's decisions. Their contributions were documented in the previous section concerning 'investigating current information'. Parents will be referred to in the section "Remembering Past Cancer Experiences": fourteen of the fathers and seven of the mothers are deceased. The concern demonstrated by mothers (143 text units) and sisters (197 text units) was not always solicited or appreciated.

The majority of the brothers' involvement was previously discussed in the section concerning family members who suggested websites, and all other references focused on the encouragement they extended to their sisters (80 text units). As stated before, most of the fathers had already passed away, and Liz was the only participant who made a specific reference concerning her father (11 text units). She mentioned that he was from the Christian Science Church, which

affected how she and her sister related to the power of healing versus medical interventions, since they both refused breast cancer therapies.

Table 9: Interactions with Family and Friends

SUPPORT	Spouse	Children	Mother	Sister	Brother	Father
Text Units	588	514	143/95=238	197	80	11
Response	75%	80%	50/45(D)	75%	45%	5%
Participant						
Audrey			D		*	* D
Bernice			D			* D
Carolyn				*	* D	*
Dominica						* D
Ellen			D			* D
Faith			-			* D
Geneva	-		D		*	* D
Helga	* D		-			* D
Irene			D			* D
Jocelyn	-		-			* D
Kim			*		*	*
Liz			D		*	D
Michele			-	D	*	*
Odette	*	*		*	* D	* D
Pamela			-		*	* D
Querida	-					* D
Roseanne	*		D	*	D	* D

* Indicates that they did not have any text units in this category.
D Indicates that the person was deceased.
Blank boxes indicate text was recorded in this category.

The exchanges were not always supportive because family members feared that the breast cancer might recur. Therefore many women found themselves either justifying their choices to family members or accepting therapies they had planned to refuse.

Husbands

Husbands are usually the first ones to know that the woman discovered a breast lump. They usually encouraged their spouse to get the lump examined. Nine of the twelve husbands accompanied their wives to all of their medical appointments. The women acknowledged how difficult it was for husbands.

> I think it doesn't matter who this spouse is, whether it's male or female. The one that is the healthy one, and watching you go through everything, they need a lot more support than the person that's actually doing it. I really do. And they don't want to put any more pressure on us. And it must be really tough. (Carolyn)

Pamela's husband was so shocked by the news of her breast cancer that he lost almost all his hair the night he found out. His sister-in-law had recently died after 2 years of battling liver cancer.

> I think he just thought, maybe that was going to be the same thing with me! But I had read about breast cancer and stuff, you know. Men don't read those kind of articles, but women do. So I kind of had a feeling that there would be, you know, a way to look after it, and you know, and hope for the best! That it wasn't in the lymph nodes and stuff like that. But he just went into traction and he lost his hair the next day. (Pamela)

While the majority of the spouses accepted their wives' decisions, six of the women said that their spouses needed to be convinced that their choices were justified. The husbands started out being non-supportive but became supportive when they talked to the "experts" or read material confirming their wives decisions.

> Oh, my husband was pretty upset about it. He wanted me to do whatever the doctors say, because what doctors say is carved in stone. And then when I showed him all the statistics, and there isn't, not that much difference between radiation, and with radiation therapy and no radiation therapy. So, I opted to, again, you know, save it for the big guns, and try to explain that to him. And then he just said, "Well okay, whatever, I am behind you." (Ellen)

These women said that their husbands were not risk takers and that they preferred to follow the advice of the medical professionals. The women wanted their husbands to explore the option of refusing chemotherapy and agree with their decisions.

> I wanted him to be supportive, or to understand what I was doing. So I brought him with me to see the psychologist. And we had a really good discussion. And I think he felt more comfortable. Because he is more apt to do what he is told! If the medical professional says, "Do this." He is more apt to follow it. I am more of a risk taker. (Faith)

Faith was successful at getting her husband "on side", and they did "take a stand together" and faced the oncologist. There were situations when the women wanted to refuse treatments and their husbands thought otherwise. So the women opted to reduce their husbands' anxiety levels and accepted the treatments.

> I know I considered not taking my last treatment (chemotherapy). But, he really wanted me to. For HIM that was assurance. For me it was just another treatment that I didn't really want to go through because by then you know exactly the routine. But it was my last. But that was probably the only time that I was frustrated. Didn't want to do it. (Carolyn)

> My husband was tearing his hair out. He was just, you could see, he was just vibrating, he was really upset. He wanted me to take it (tamoxifen), and he knew I didn't want to and he said, "I won't try and convince you. If you feel strongly that you don't want to take it, don't take it." And in fact, when they gave it to me, I delayed for a month, I didn't take it for a month after they gave it to me. And, I am still not sure if that was the right decision. SO, I've been on it for three months now. (Audrey)

One husband had a previous experience of supporting his first wife who died from metastasized breast cancer. His wife made it clear that this was not a joint decision.

> My (second) husband was right there with me. But his first wife died, of breast cancer. So, at first he was very, very fearful that I wasn't just doing, you know, slamming everything into me that needed to be done. Now he

> went full circle with me and has a very different viewpoint about the healing process. But he was just in a different place. I mean he wasn't saying "No". He was just saying he was just afraid. (Bernice)

Once the husband "gets on board" with the woman's decision, they become very active themselves during the appointment with the oncologist.

> I thought, "There's going to be bloodshed here in a minute." But afterwards I had to talk to my husband and say, "You were intimidating him [oncologist]! And he [husband] was on his [oncologist] turf." I said, "You don't know how many people he has to tell in a day that they've got cancer! And you don't know how many husbands he's had to tell where their wife had breast cancer. And these guys could have jumped up and knocked him in the face! You know, you've got to appreciate that he was just as uncomfortable as you were." (Liz)

> He went in with me to talk to the doctors, he was pretty vocal about the tamoxifen. Cause we discussed it. He told the oncologist that we had put a lot of thought into it and that he would go with whatever I wanted. And I said I didn't want tamoxifen. (Carolyn)

As stated in the section on 'attaining a second opinion from specialists', the women were sensitive to the fact that they want to maintain their ties with the oncologists in case they need them in the future. As one woman said, "It is a fancy balancing game."

Two women mentioned that they relied on their husbands' medical expertise and ability to decipher the statistical information that they were reading.

> The statistic was thrown out there, now what does that mean? And as we sort of looked at things, he was very helpful, and basically, from the beginning, he said, "This is your body. It's your life. It's your choice. I'll support whatever you decide to do." That was his starting point. And the ongoing information really confirmed for him that I was doing the right thing for me. So he was 100% supportive. (Liz)

> My husband not only went with me, but he is a physiologist. So, again, he's got this very, very strong scientific, medical background. But for the last 15 years, he's been on this sort of spiritual, Buddist, Taoist path. So,

> he was the one that encouraged me, when I first started the Adriamycin and the cyclophosphimide, to turn to complementary. (Kim)

Three husbands preferred alternative medicine and played active roles in trying to justify their informed refusals to the medical professionals. Michele's husband had also supported Michele's sister who died from metastasized breast cancer after receiving conventional therapies.

> We went back to the Alternative Medicine Research Centre and had a long consult with the doctor. And we had a consult like the next day with the oncologist. And we had decided that the chemo and radiation is just too radical, just too hard on my immune system. We tried to explain that to the oncologist. He wasn't very understanding though. He basically said, "Well if you don't do the chemotherapy, you will die of breast cancer." And I said, "Well, I don't agree with you." So, then the oncologist, he said, "Well I'll still work with you if you want me to." And we said, "Okay, that would be fine." (Michele)

Women commented on how their husbands worried about the financial burden that resulted because of their wives' unemployment due to breast cancer. Career changes were put on hold for three husband's who decided to wait, in order to ensure the continuation of medical benefits. Two women talked about the resentment expressed by their husbands when they had to hire housekeepers. These women wanted to return to "normal" as soon as possible, so they weighed the benefits of the therapies against the burden of taking more time off work.

> I know that then he transferred his anxiety about me over to MONEY! The money situation had to be resolved! He had to work. He was working 7 days a week, and evenings and weekends. And just anything he could get. He was just overextending himself something fierce. But he said, "We've got to do this! We've got to build a nest egg." Which we did! But at great cost to him physically! So I was getting better and he was wrecking himself. (Pamela)

Pamela's husband was instrumental in finding the newspaper article that recommended fewer radiation treatments for her stage of cancer. He suggested it

because he was concerned about her burnt skin after only one week of radiation. Her husband took control over explaining "their decision" to the oncologist. He accompanied his wife to the radiation oncologist and he said, "We have decided to do 3 weeks instead of 5. That's how it's going to be." As mentioned previously, this assertive behavior on the part of the spouse was common.

There were continual references to the tireless support of husbands and their ability to bring humor to the situation. Men shaved their heads when their wives lost their hair. They went to the chemotherapy sessions and handed out candy or donuts to the nursing staff in the hopes of "securing adequate care".

> My husband was always bringing donuts, you know, before chemo. Cause maybe then, in exchange, one nurse would be with me from beginning to end, and get me started, and it wouldn't take two hours of sitting there before the drug was started, they started to push through the first drug. (Faith)

According to the majority of women in this study, their husbands supported them more than their doctors did, even though their husbands had more to lose if their wives died. They respected their wives' decisions more than the doctors, who might never see them again. It is her body, her life, her choice. Wives and husbands held hands and cried together, as they discussed their children and their choices.

Children

The women's children ranged in age from 2 to 45 years of age. The majority of the women's offspring were adults: nine were in their 20's (five mothers, one step-mother), fourteen were in their 30's (eight mothers), and four were in their 40's (two mothers). Eight of the children were teenagers (four

mothers) and seven were under 12 years of age (four mothers). The women's illness produced very different reactions in the different age groups.

Beginning with the four women who had children under 12, the burden of making a decision involved increasing one's life span so that they could be there for their children.

> I kind of looked and I weighed, "Well yes, I improve my risk factors if I do something. I could just leave it at the surgery and not do anything! And I have increased my life span a little bit. But if I do even a little bit more, then I increase my life span more!" So how much further do I want to go? And obviously the fact that I had young children meant I wanted to do something, I couldn't leave it. With just the surgery, it wasn't good enough. (Audrey)

The women tried to keep their children informed, just as they themselves remained informed. All of the women with young children talked about leaving books out for them in order to lessen their fears about their mother's surgery and treatment options. However, the young children could not participate in the decision making process, and the confusion and fear were engrained in their mothers' memories.

> The adopted one (she was 8), she was afraid that it was contagious. And I didn't find out until almost a year later. She really suffered with that. That's why she wouldn't come near me. I thought it was because I didn't have hair and that. (Ellen)

> The youngest (9) said, as we were sitting there discussing all of this, "Does this mean I am more likely to get it?" You know, out of the mouths of babes. And what can you say? Our answer was "Yes it does. It puts you at a much higher risk, and you have to be careful when you get older." And she was quite upset by that. (Audrey)

The four women who had teenagers were sad that these children were expected to assume more responsibility for the housework at a time when they

were also facing the reality of death. They wanted to choose treatments that would ensure that they would resume their previously established nurturance roles.

> They do all the chores. They do the dishes. I don't do anything. I just direct traffic. They have to learn to work as a team. Regardless of whether I am here or not. Because once my life is back in order, and I can accomplish more than just a half a day. I want a life back! We all have to learn to work as a unit. And work together and, we've never had to do that before. I don't want death to have to waken them! I want them to be awake before. (Dominica)

> I did feel really bad that my oldest daughter got dumped on. And I think it is just a logical thing in that she's 13 years old. I know that's one of the things I have read too, about what happens to a lot of women who do have breast cancer, it's the oldest daughter who seems to suffer the most. (Audrey)

The women were not always successful in their attempts to reduce their teenage sons' fears by negating the seriousness of their specific situation.

> He was really scared at first. Like when I first told him. I said, "I think that I am lucky. I mean I could have a much worse kind of cancer. And I am going to have surgery and I am going to be okay! If you can call yourself lucky, I guess in this department, I was lucky to have the type of cancer I did." And he was okay with that. (Querida)

> My son who is 15, I think emotionally it was probably hardest on him because two years ago, his best buddy's mom, who lives a block away from us, died of breast cancer. So his first comment to me was, "Are you going to die, like CJ's mom did?" And I said, " No." So he was very upset by that. (Audrey)

In an attempt to maintain some level of normality, the women often shifted their concern away from themselves. They comforted their young adult children because their children's greatest fears were their personal increased risk of cancer and the loss of their mother. Mothers continued their role as caregivers.

> My daughter (18) just said, "Thanks. Now I have to be extra careful." My son (21) wanted to know if I was going to die. And I said, "NO, not likely." … She's (daughter) quite big boobed, and she said, "Now how am I ever going to find them." And I said, "Well you'll be starting

> mammograms, if we can, at an earlier age." I'd like her to go through a real mammogram, so that they can at least have a base. (Carolyn)

The two daughters who were in their 20's were more informed about breast cancer than their brothers, even though their mothers told both genders to be diligent in the future concerning self examination for cancer.

> My oldest daughter has precancerous cells on her cervix, and she is very aware about this (pointed to her breast), they (the oncologists) have impressed it upon her. As well, my son, I told him, "Just because you're a guy doesn't mean anything. It's in the genes." My paternal aunt died two years. So, I am the first of this generation. (Ellen)

> With my daughter, it's been a different scenario (her son gave her a "magic stick"). Lots of talking, crying. She doesn't read books. She went out and she read some Breast Friend Companion. It was about a 700 page book she got out of the library. And in there she read about how this woman who was diagnosed with breast cancer, her friend made her a hat. And it said, "Just say no to drugs." And she knew that that would have an impact on me because she knows my harm reduction philosophy. (Faith)

The two step-daughters were extremely empathetic to their step-mother because one of them was battling a serious liver condition at the time.

The five sons who were in their 20's were concerned with their mother's survival. However, they demonstrated their support without adding any information to their mother's decision making process.

> He just said, "Mom I know everything is going to be okay." And he's just maintained that attitude throughout. He brought me back this stick because I have always said that I have these magical powers. So, he brought this stick and I was to do whatever I needed to do, but the stick was going to give me the power to cure myself. And I was just supposed to do this spell and go (Whoosh sound). (Faith)

> Some friend of mine met my son at one point after I had had the surgery, and she said, "Well how is your Mom?" And he said, "Well, she sure seems fine! She's doing this, she's doing that." He's caring and loving, but he just really doesn't want to know the details. He just wants to know you are okay. Where my two other children (son and daughter in their 30's) are right there in the thick of it, asking the questions, you know balancing one

> thing against another, "What about this Mom? What do you think?" (Bernice)

Five of the children who were in their 30's assisted their mothers by researching information and/or referring the women to additional health care providers.

> My son also works at the University Hospital and he is a lab technician. I came home, and I said to my daughter and oldest son, "I'd really appreciate if you would take all of that medical information and line it up again for me. I think I understand it, but this is your area of expertise. If you would do this for me, I am going to do what I need to do." (Bernice)

> I had been to a friend who's an oncologist, on the advice of my son, he paid for this woman. (Jocelyn)

Conflicting views among the older children concerning traditional and alternative medicine created additional stress for the women.

> He's (oldest son) very much into the homeopathic. And he goes to an acupuncturist. He's a really different kind of guy too, and I guess he went to talk with him (the homeopathic doctor), and he said, "Well here's a list of stuff she should be using." Then my younger son said, "My neighbor, who has taught pharmacology at the university for many years, brought over this information all favoring radiation." They (her son and his wife) had decided that I would have the radiation. You know what a fragile state you are in at that time! Like a month after surgery. And so it's like, Oh God! He's saying this and he's saying this! And my oncologist says this. (Irene)

When one woman said she was refusing all medical intervention, the oncologist said, "Well if you won't do anything else, will you do the tamoxifen?" She accepted the drug, not because of the oncologist's request, but to placate her children.

> My family would say, "Well you're at least going to take the tamoxifen, aren't you Mom?" So it's sort of like a pacifier. And part of me would like to let go of that! Because I don't think I need it! Because I sense that I am WELL! But I haven't reached the point of being able to do that. And mostly because of the connection, and sort of a commitment, you know to my family. (Bernice)

However, there were women who felt no obligation to accept or solicit input from their adult children who now had families and responsibilities of their own.

> My sons were far away, and when I was making the decision, it had a lot to do with where I am in my own life. In my case, my sons were grown and gone and living far away, and beginning to establish themselves in their independent lives. I felt like I have sort of accomplished already many of the things in my life that I have wanted to do. I've had so many blessings, if it's cut short, I really haven't missed anything. So that really gave me freedom to make that decision. But if I had been looking at young children, that still needed me, I would have been terribly torn. Because I would have felt this is not my decision, to make my body mine, my life. This is going to affect their life hugely. (Liz)

There is no doubt that a mother's decision concerning breast cancer therapies is profoundly affected by her relationship with her children. And just as the women remembered past cancer experiences, so too will their children.

> The whole process, there's no question that it just drew us, I mean, closer than we already were. And then it feels like with all of them that we had that scare, and here we are, I'm alive and well and healthy. And so that's over. We've made it through another crisis. But I am sure that they are far more, they couldn't help but be more aware than someone who hasn't experienced whatever it is. (Bernice)

Mothers

The role of the mothers of the women with breast cancer was more protective than informative. There were three distinct responses identified by the women: they judged, they worried, or they provided emotional support. Mother's of the women in their late 30's and early 40's were more critical of their daughters' behaviors.

> I know that this implant isn't going to last forever, and I know that there are risks with it. That's something that I had to tell my mother to quit telling me! I have it in my body already, so quite telling me, there is nothing that I am going to do about it. It's in there and I did it because I needed it. (Michele)

> I couldn't lift my arm up here because of the swelling. And, so my Mom and my sister were saying, "You should be doing your physio!" And meanwhile my doctor was saying, "Don't push it. There's something happening." (Faith)

The women who anticipated that their mothers would worry were selective about the amount of information they would tell their mothers in an attempt to reduce their anxiety and limit their mothers' advice.

> Fortunately, my mother didn't live in the area where I lived. And you know, that was good. We would talk on the telephone. And we were close enough. But my family were kind of overbearing people, very protective. And so I would give them enough information just to set them off. And of course, Mom panicked when I said I was still going to work. You know, "You shouldn't do that! You should be resting more." "It's my body, I'll do it my way!" You know, and they kind of let off. But they did have a few things they thought I should know, and I said, "I know about that." (Odette)

> I actually didn't tell anybody in my family either, until I actually knew the results. You know, it came back saying that there was no aggressive cancer, it was just calcification and stuff. So then I phoned my Mom. (Querida)

Some of the women solicited their family's support to help them shield their mothers from the truth.

> I told my sister, "I don't want to tell mom because she just buried Dad. So after the surgery I said, "Well Mom, they took it out and then they sent it to a lab, and I guess they found some cancer cells in it." Like after. Well then she went minor ballistic, like, "Cancer! My God, it's cancer!" I said, 'Mom, settle down. It was a very, very small little, half a marble size. And it is not in my body, they took it out. "I DO NOT HAVE CANCER NOW." But in the meantime, she got herself a couple of breast cancer books and she was reading. Oh God! I had to field some phone calls and that. And I had to reassure her more than once. (Pamela)

In contrast, the mothers who were over 80 years of age offered a more sympathetic approach to their daughters' breast cancer.

> Mom and Dad, it was very hard on them, very tough, because Mom said "Why not her? She's old." And I said, "Mom, it doesn't pick old people! It's a young disease. (Carolyn)

> I think, just from a female point of view, she was quite upset. And she didn't say a lot, but she was there with hugs and kisses and stuff like that. So, I just sort of. And I guess, typical in her fashion, going, sort of holding my hand, squeezing my hand. Saying, "You know, you can do this! You know you can do this." So that was good. It keeps you strong. (Querida)

Helga's and Jocelyn's mothers had Alzheimer's disease and required care from their daughters who were both in their 60's. They felt responsible for their mothers and worried about their future care should the breast cancer prove to be fatal.

> I had Mom here and it was cold and snowing, storming. My doctor called me saying "I want to see you right away." So, of course, I took Mom over to my sisters, rushed down there to the doctors. (Helga)

The mothers were not as involved in the reviewing process as sisters because the women were selective about the information they shared in order to protect the mothers from becoming distressed, and protect themselves from receiving lectures. Once a daughter, always a daughter.

Sisters

All of the women in this study had sisters except Roseanne: She had one brother who died six years ago. Even though the sisters were shocked by the news of their sisters' breast cancer, they provided support and expressed confidence in their sisters' decisions.

> She was quite traumatized, because I only have one sister, that's the only family I have. We are quite close. She basically dropped everything and came. She has been a hundred percent supportive. "You have to make these decisions. It's your life." When I laid out the decision for why I wasn't going to take chemo and stuff. She said, "That's the risk you take." (Audrey)

> When I told her I wasn't doing the chemo or radiation, and she just asked a few questions, and it was, "If that's what you need to do, that's what you need to do." It was just that simple. And that's exactly who she is. "You thought about it, you're intelligent, then I guess it's the right decision for you." (Bernice)

When the woman was the first in her family to have breast cancer, she felt it was her responsible to inform her mother and sisters to be on alert.

> My sister was right on to the phone. And provided support and didn't question that I would be doing the right thing. She's my younger sister and has always assumed I knew where I was at! But of course one of the first things that occurred to me, "Oy yoi yoi. I started something here!" So, they are warned, well warned. (Liz)

The success or failure of the women's decisions plays a huge role in the subsequent choices their sisters make when they find a breast lump.

> When I got diagnosed I started worrying about my sister, because I learned that the highest risk group is a pre-menopausal sister! Pushed her into getting her first mammogram, shortly after I was diagnosed: "Well look at that. Oh my God! This little shady area over here." So I have been working with her, slowly. Over the last four years, I have got this little (alternative therapy) regimen going for her. And she went back for her fourth mammogram last year, and that spot is gone! And she said, "Well, I have been working with my sister. This is the regime we have put together as preventive. And it's totally eliminated the shading off the mammogram. (Kim)

> My sister also had something strange going on in her breast and they did some tests and were concerned that she might have a type of cancer. And she was being very cautious about just letting them do anything at all. Was more inclined to say, "You'll have to convince me that it's necessary before you go any further". So we are both tuned to this, and I think maybe my example might have confirmed what she already knew. (Liz)

Helga's sister experienced breast cancer 10 years prior to Helga's diagnosis, and she is still alive. Since she had a mastectomy with no further therapies, Helga also refused chemotherapy and radiation therapy, and questions the value of the tamoxifen because her sister does not take it. As mentioned

previously, just prior to Michele's diagnosis, her sister had breast cancer and died. Therefore, the other sisters thought that they should have genetic testing. Michele tried to calm their fears by joking, saying that statistically, she and her sister had already "filled the quota for breast cancer in their family."

Conflict did arise for one woman because her sister's philosophical view differed from Faith's more preventive and compassionate approach to health care.

> My sister's really bought into the medical model. She works in emergency and intensive care. But my sister said she was concerned that I was becoming a junkie, and it has challenged our relationship to this day. (Faith)

The future decision making processes of the sisters will be shaped by what they witnessed during their sisters' decisions making process and by what they heard when their sisters justified their health care choices.

Listening to The Internal Dialogue

Seeking answers required time to seek and absorb past and present information. Each woman carried on an internal dialogue that was shaped by her memories of previous cancer experiences, perception of the causes of her breast cancer, and assessment of her body, mind and/or spirit. Then they would spiral back to their information sources as they continued to fill in the gaps and reexamine their options.

Remembering the Cancer Experiences of Others

This part of the process involves remembering the cancer experience of significant others, analyzing personal responses of fear and sorrow, and comparing their circumstances with their memories. When the women explained

their cancer experiences, their stories included recollections about their family members who have either survived cancer or passed away. Ten of the participants have immediate family members who had breast cancer. Several women talked about when they were young and their mothers passed away, and how deeply that memory was reflected in their present situation.

> I lost my mother to stomach cancer and she was 43. So she was young. At that time cancer, anything like that, was very hush, hush, and we knew my mother was very sick. We didn't know how sick she was. Of course the first thing my doctor wanted to know was my medical history and I said I can't tell you cause I don't know. My father would never discuss it. So, my doctor went and researched what my mother's medical history was, so I would have it, and my sister would have it, because obviously, she is at risk as well. I went through my life, not knowing, and not understanding. I won't do that to my kids. It's too frightening. (Audrey)

There is the fear that "history is repeating itself." The woman's family is now considered to be at a higher risk for cancer, and as stated by several women "it's in the genes". Two women who were adopted felt that it was imperative that they inform their "biological family" because they too should be diligent about checking for breast cancer.

Several women remembered when their mothers had to explain that they would not always be there for them. Now they find themselves faced with the possibility of leaving their own children. One woman who accepted chemotherapy but refused radiation and tamoxifen said:

> All through my chemotherapy I thought of that incident (her mother explaining that she was going to die). I was trying to prepare my children, and I was thinking that she was trying to prepare me. (Ellen)

Faith and Pamela had experienced the deaths of their sisters-in-law from cancer just prior to their own diagnoses, and Michele's sister died from breast cancer just

a few months before Michele's diagnosis. For these women, there is the added burden of wanting to reassure their children that their cancer is not as aggressive as their aunts' cancer.

> We had to explain to the kids that they did find something that they thought was cancer and explained to them, it's not the same as Auntie's. And that I am not going to die, and so they were pretty good about it. I mean, they were kind of scared. And especially when I had to keep going back in for surgery and they were kind of freaked. (Michele)

There were two women whose husbands had died prematurely from cancer over twenty years ago, and they had adult children that feared losing their mothers to cancer. These women both recognized that while they were dealing with a less aggressive cancer, they feared the chemotherapy and were not keen on accepting such invasive therapy.

> Just to backtrack, my husband died of cancer, it happened really quickly. And when he had his chemo, that was in the early 80's, it was a different time in the sense that what was available. And I knew that part of my reaction to the whole thing around chemo was the remembrance around what he experienced. And so I was well aware that what I was initially responding to was a fear of the chemo, period, okay! And I recognized that, I knew that, I named it. (Bernice)

These women remembered the pain and recounted the details of their husbands' surgeries and chemotherapy, the reaction of their children, and the social isolation that surrounded their loss.

Many of the women had stories about their relatives who were "opened up and closed up again because the cancer was everywhere." The fear that death follows swiftly after the diagnosis of cancer remained in their minds. However, there were also success stories, where mothers, grandmothers, sisters, sisters-in-law or aunts had experienced breast cancer and survived. One woman called her

mother-in-law a "walking miracle" because she had a double mastectomy years ago, continued to live a full life, and was a "real positive role model." As stated previously, Helga's sister is a ten year survivor of breast cancer, so Helga had this to say about women she knew who had breast cancer years and years ago: "They just had it removed and that was that, and they are still here."

The cancer stories from friends had a huge impact on the women's choices. Geneva talked about her friend who had cancer: "At first she only had a lumpectomy, and then another lumpectomy, and finally had a mastectomy because by that time it had already moved to her other breast." She said she wasn't going to fool around like that, she was going to have a mastectomy. Several women commented on their friends' traumatic cancer experiences, including heart damage from the chemotherapy or severe radiation burns.

> I think my decision about radiation probably started about 40 years ago when a friend of my mother's, this would be late 50's, had a mastectomy. And then had radiation. She became so ill from the burn, from the radiation, that I remember her saying, "If I had known it was going to be like this, I never would have agreed to have it." And even NOW, women at this support group were talking about the terrible burns. So, it isn't that it has become improved! It is the same DAMN thing! And, I am not going to be somebody's guinea pig! (Roseanne)

This woman is a nurse, and she said she would rather have a success story that did not involve the medical system. The past experiences of cancer also influence their present understanding of themselves as women who have cancer.

Speculating on the Causes

The women pondered the question, "Why me?" as they searched for an understanding of their specific situation. As the women speculated on the causes of their breast cancer, they considered several possible explanations that

correlated to (1) genetic flaws and hormonal interventions, (2) lifestyle choices that compromised the immune system, and (3) environmental toxins that contributed to the growth of cancer cells (Table 10). Each woman's perception of the cause influenced her perceived ability to control the spread or the recurrence of breast cancer.

Table 10: Possible Causes of Breast Cancer

Time of Life	Genetics and Hormones	Compromised Immune System	Environmental Toxins
Conception	Genetic Type AB blood	Weak Link Predisposed	Air pollution Water pollution Pesticides Radiation Mercury Modified food
Adult	Birth control pills	Emotional stress Work stress/Care giver Poor diet Smoking Under-wire bra	
Mother	Breast feeding: Dry up pills Late pregnancy		
Menopausal	HRT		

Genetic Predisposition

Genetic factors are inherited and predispose the carrier to breast cancer. Ellen was convinced that her breast cancer was genetic, and that this weak link existed from the moment of conception. This explained why there were people who could smoke and drink all their lives and never get cancer; they did not have the weak gene. Therefore, she would not consider radiation as a form of therapy because she believed it would trigger further growth of cancer cells. Irene read that women with her blood type, AB, had a weaker immune system that predisposed them to cancer. She felt that the additional strain created by a stressful relationship with her mother and constant tension in a care giving work environment was too great for her genetically compromised immune system. The

logical solution from her perspective was to boost her immune system with holistic medicine.

Hormonal Interventions

Women under the direction of their health care providers introduced hormonal therapy that they believe affected their breasts. Several of the women attributed their breast cancer to hormones that they introduced in the form of birth control pills, drugs to reduce engorged breasts, and/or hormone replacement therapy (HRT) to reduce menopausal symptoms. These women said they were not initially informed of the risks of the hormone therapies.

> I was also on birth control pills for 10 years. And I was on them when they first came out and they were really high doses of them. So, to me, like I look at it and I think, "Why are there so many women with breast cancer?" And younger women are getting it! I mean, maybe in the past, women got it when they were older, it was slow growing. They passed on from other causes before the breast cancer had time to have any effect. I don't know. I am really thinking that it's the use of birth control pills. Even though my cancer wasn't hormone sensitive, it still is hormone related. (Querida)

Issues surrounding breast feeding were also thought to be related to breast cancer. Carolyn had problems drying up after nursing her child and she wondered if the drugs contributed to the breast cancer. Querida and Audrey both explained that they were told they would be at a higher risk for breast cancer due to their late pregnancy, and that breast feeding would help.

> The doctor said, "Because you are an elderly mother, and you have all these risks of cancer. Breast feed." He said, "Breast feed, it will do wonders for you." So I breast fed all four kids to reduce my risk. I did everything possible, to prevent this happening in my life, and for what? (Audrey)

Querida was also disappointed that nursing did not make a difference, and she said "I am not even sure that when I was nursing him, that it hadn't started

already. Because when I look back, in hindsight, he was sort of very fussy on that side." She had a miscarriage three years later and she believes that gave her a "shot of hormones and all of a sudden it gets cut off and it messes up your body."

Dominica thinks that her cancer started growing inside of her because of the hormonal changes that occurred during pregnancy.

> My hormones changed and that's where I figure it all started was then! As soon as I had children. I think that in those thirteen years, with all the anger and stress and resentment, and all that, my mood swings got more frequent. Which was a hormonal imbalance right there. (Dominica)

Bernice and Jocelyn both had a strong sense that the hormone replacement therapy increased their estrogen to unsafe levels. All of these women felt frustrated that they accepted medical advice with the understanding that they would be safe. These experiences affected their decision when they were offered the chemotherapy drug tamoxifen, which blocks the hormone receptor sites.

Compromised Immune System

While the women described above felt that their breast cancer was the result of their genetic flaw or hormonal interventions, other women had heard that everyone has mutated cells in their body and a healthy immune system removes cancerous cells. They identified additional factors within their everyday life that compromised their immune systems and activated their breast cancer.

> I think the cancer was caused through many things. I think the holding of anger, I think my diet, I think the things that we don't know about that are in our atmosphere, and I certainly have experienced major losses in my life, and you don't know where that's being held in our body. I didn't read Bernie Siegel's "Anatomy of the Spirit" and think, "I know what caused my cancer." I have the sense that this cancer lies dormant, and THEN if the conditions are right, it activates itself within the body. (Bernice)

Emotional stress, poor diet, smoking, trauma to the breast, and even under-wire bras were identified by the women as contributing factors. The condition most consistently stated as the cause of breast cancer was *stress*.

Several women mentioned having to deal with recent deaths in their families: mothers, fathers, sisters, brothers, and aunts. Since Michele's sister recently died from metastasized breast cancer, she looked for similarities between them. They were both young and extremely conscious of their health, so she thinks that cancer is more of a mind-body disease, rather than just a physical illness.

> I think it has a lot more to do with how people deal with stress in their life. The only thing I can think of is, they talk about people that don't speak out enough, that you know, keep their feelings hidden. And I think, well both my sister and I were kind of similar like that. We would keep a lot inside of us and if people really bugged us, we wouldn't really say anything. We'd just say, well, it's our problem, we'll get over it. So that's what I kind of think. So I've been working on that a little bit more. (Michele).

Pamela was convinced that massive amounts of stress at work and home caused her immune system to "snap". Querida and Jocelyn thought their immune systems went "out of whack" because they were dealing with unhappy relationships that subsequently ended in divorce. Roseanne said, "I was in a position that was not necessarily all that good for me, and that I had probably outlived my useful time there." Twelve women referred to previous work situations where they were in the "service of others". As a result of the breast cancer, they are now trying to nurture themselves instead, to avoid a recurrence.

Nine women mentioned unresolved maternal issues that they felt were connected to their breast cancer: five women mentioned difficult relationships

with their mother and four women spoke of dealing with their mother's death. Liz relates her cancer to her dysfunctional relationship with her mother.

> I was seeing this psychologist around mother issues. And we realized that this was a real mother issue all over again. And you know, I had things to learn from it and did the intellectual work to really come to understand some of the stuff. Around who my mother was and why she was the way she was and how that had affected me, and why I was transferring some of my angst and blah, blah, blah. And that was fine so far as it went, I understood. But I didn't really deal with the feelings. And I think the cancer came along and said, "We have to deal with the feelings!" (Liz)

Geneva, Helga, and Jocelyn were all responsible for providing care for their elderly mothers, which they believe has taken its toll on their own health.

Breast cancer is thought to be a "Wake up call" by many women. They drastically change their diet in an effort to boost their immune systems, detoxify their organs, and create an internal environment that is not conducive to cancer growth. If they believe that their cancer is caused by stress, they introduce exercise, meditation, yoga, massage therapy, and visualization into their lives. Many women leave harmful relationships and draining work situations. A few of the women are still smoking and feel guilty for not being able to quit.

Environmental Toxins

All of the women were concerned that they do not have any control over the external environment and they worry about pollutants in the air, water and food. However, they did not identify a particular factor in the environment that they thought might have created the growth of cancer cells within them. Instead they thought that the environmental toxins added additional strain to their compromised immune systems, which they felt personally responsible for

maintaining. Michele believed that we can all overcome the causes of cancer which are inevitable for everyone.

> My whole attitude is, everybody is going to get cancer. I don't care who you are and what you are doing, or whatever. Everybody is going to get it. And it is how you chose to live your life and whether or not it is going to affect you in a large or a small way. It's up to you. But I think everybody will get it. Or everybody has it. It's just whether or not their body is fighting it or not. Because there's way to many things in the world that are carcinogenic. There's no way that people can not have cancer. I don't think of myself as a special case. I think of myself as the norm. (Michele)

There comes a point when the women look at themselves for further information, whether they believe that the cause of the cancer was related to genetics, hormones, stress, or the introduction of some toxin. This leads to the next section of this study: assessing the body, mind and spirit.

Assessing the Body, Mind and Spirit

Every woman who is told that she has breast cancer is informed about her five-year survival rates, based on the size of the tumor and the axillary node involvement. This evaluation is used to make the decisions regarding treatment. Each woman in this study wanted to know what risks and benefits of the prescribed therapies. More specifically, she wanted to assess the changes that may occur in her body, her mind, and her spirit.

Body

The most obvious physical change associated with breast cancer involved the surgical removal of breast tissue and lymph nodes. Even when the surgeon explained precisely how much tissue would be removed and what the woman would look like afterwards, it still seemed like an unreal and overwhelming choice.

Surgery

There was a marked distinction between the women that chose breast conserving surgery or mastectomy *with* reconstruction and the women who opted for a mastectomy *without* reconstruction. Breast conserving surgery was preferred by the women (and their surgeons) when the tumors were small and there was no lymph node involvement. Four of the eleven women who chose to have a mastectomy resolved to have breast reconstruction to maintain a sense of balance and to make themselves feel more complete.

> I wanted to be even! You know, and so that was important to me in my own feeling of being a woman! So I choose to do that. It was really very simple! (Odette)

> It became clear that I couldn't have plastic surgery if I only had a partial, part of the breast removed. It's not just a breast. Because you know, you feel more complete when it's there. … So I decided to go with the saline implant surgery because that seemed to be the simplest and it would heal. (Querida)

Even the surgeons recommended reconstruction, especially for the younger women who had a professional image to maintain.

> He (the surgeon) said, "Forget anything related to breasts and implants and all this stuff that's associated around, 'Well you must be really vain if you want to reconstruct your breast.' That shouldn't be important. Think about it as just bringing your life back into balance and wholeness." The other thing he said is, that a lot of women don't really think about the fact of removing a breast, the effect that that has on your posture and your whole balance. (Kim)

Conversely, the eleven women who had mastectomies without reconstruction mentioned several reasons why they did not want to replace their missing breasts.

> As soon as they diagnosed and said mastectomy, I said I wouldn't go through surgery again. And that was even before it was taken off. I am just not going to take that chance. If there's something stray there and it's sitting dormant, I'm not disturbing it, not for anybody. Sorry, it's gone, I don't miss it. (Carolyn)

> That's the thing that scared me too about getting an implant, because they don't read well in mammograms. How do you know what is going on underneath? I don't want to have the tram flap. I just think AHHH (high scream). I know it's my own flesh and everything, but it's very invasive. And there ain't no goin' back. No I don't want to do it. I think I am just going to be like, I don't care anymore. I just want to live, you know! (Ellen)

> He (surgeon) said "You could have a re-construction but you don't really need it." I said, "I don't think I really want it." I said "My time of having babies and feeding them, that's in the past. And I can make myself look as attractive as I want without having any kind of re-construction." (Geneva)

The surgical removal of the lymph nodes was a greater concern for most women than the mastectomy or lumpectomy. Eleven of the women mentioned that their arms were compromised by the numbness, increased risk of infection, and the constant threat of lymphedema from over exertion.

> Six months after I had the mastectomy I went in and had my lymph nodes checked, and they were negative. So, it was a high price to pay for a little bit of peace of mind. But I think it was worth it! You know, I mean the lymph node surgery is far more debilitating than the mastectomy. (Querida)

Three women had no problem with their arms after the surgery and Faith was relieved that the lymph nodes were removed when she learned the cancer had metastasized to the lymph nodes. The price Liz paid for insisting that the lymph nodes remain intact was a larger lumpectomy.

> He (surgeon) went in and did an incision again and by this time I had told him that I was not wanting to have the lymph nodes examined. … He told me after he had done the surgery that he had taken a slightly larger section than he might have to be sure that I had clear margins. He said, "I know you are having thoughts and we might as well get as much of this out as

> we can." So he took probably about a quarter to a third of the breast in a section. (Liz)

Jocelyn had made a similar request to have only the sentinel node removed. And even though the surgeon originally agreed to her request, she did remove the nodes and they were all negative. This diminished her trust in the surgeon.

> She (consult with one surgeon) said, " You don't need all of those lymph nodes removed." So, I told this woman (second surgeon) this, and she said, "You have to take them out." So I said, "No!" I told her I don't have to take them all out. So she said she would have to take at least the ones under here. And I said, "Nope, I don't want as many as you want taken out. I just want the sentinel node." So, anyway, we left it that as few as possible would be taken out. And I thought that would be three to six.... Then I went in and did surgery and came out and when I had come out, she had cut them all out! Right! And I am furious. I wanted to commit suicide that night. So it was a terrible thing of betrayal I think. (Jocelyn)

After the women experienced the effects of surgery on their bodies, they have to internalize the ramifications of choosing further side effects from chemotherapy, radiation, and/or tamoxifen.

Chemotherapy

Every woman wanted to know what the risks and benefits of using each adjuvant therapy. For several women, they felt there was little doubt that the surgery had removed the cancer, "So why wreck your body for one thing, to get 5% more coverage." Because of the risk of heart toxicity from chemotherapy, Audrey and Ellen decided there was a greater risk of immediate death from a heart failure than from cancer: "See if your heart is strong enough so we can wreck it" (Ellen).

> The oncologists said, "We are not sure that you can have chemo because you are only six weeks out of heart surgery and we know for a fact that one of the chemo drugs is really hard on the heart. So we don't know if you should do that." (Audrey)

Faith had first hand experience of heart toxicity from chemotherapy, but she was not taken seriously until she insisted that they investigate her side effects further.

> The Adriamycin started affecting my heart, and I could feel it affecting my heart! I could feel the pain. I could, it felt like a hand at one point was gripping my heart and squeezing it. It was very intense. And that was just one of the symptoms. I had numbness from my shoulder all the way down my arm. But when I would tell people that I could feel those things, I was told I was anxious. I was told I was just imagining it. (Faith)

Dominica had one chemotherapy session before she chose to stop taking chemotherapy. She described her experience of losing her hair and the possibility of damage to her liver and kidneys.

> I could tell after the first time that I washed my hair after my chemotherapy treatment which was probably three days after I managed to have a shower. I could feel my whole body changed. I could feel the drugs going through my body. I had no feeling in my legs. My fingers tingled. My face got so hot that it felt like it was burning. And my skin changed, it was dry. Deep down inside they don't tell you that there's no guarantee with all of this. And that you could get cancer in your liver. It's always the liver it attacks, because your liver is your filter system. And if you don't get all the chemotherapy drugs out of your liver, then it becomes weak, right. With one of the drugs, the woman told me to drink lots and lots of water. She said, "More than 8 glasses of water" she says, "Because it just sits in your kidneys, it will cause them to bleed." (Dominica)

The women described the abrupt termination of their menstrual flow as "chemopause". Along with menopausal symptoms, the women also experienced severe mood swings from the dramatic shift in their hormones.

> Some of these younger girls, does it (menses) come back or no? I'm sure it can't because, how in the world, after what your body goes through, is your body going to be functioning properly if it throws you into menopause? Even if you're only a tiny bit perimenopausal like I was, whack. It's over! (Carolyn)

> I went to her (psychologist) and said, "This chemotherapy seems to make me cry a lot!" And she said, "Yes! It does affect you hormonally! It could also be grieving, but it does affect you hormonally." And I said, "You have no idea what a relief that is." ... People thought I was really depressed. And, I didn't know what it was. And here it turns out it was the chemo! (Faith)

The women who refused chemotherapy could not justify the risk of "going through all that misery for 1 or 2% greater chance of survival".

Radiation Therapy

The risk of radiation damage to the heart and the surrounding bone was considered to be too great for ten of the women. Two of the four women who did have radiation therapy described the severity of radiation burns.

> At night my radiation burn would come out the worst. But the skin is very compromised from all of this, the chemo and the radiation and as a result it just left me more susceptible to everything after the mastectomy. At night time, it turns very purple.... It's probably two-thirds less red and swollen and everything else than what it used to be. About a week ago, I couldn't lift my arm up here because of the swelling. (Faith)

> I had a little problem with peeling and burning anyway, but nothing compared to the horror that I have seen on women's bodies from our group support meetings. And the INFECTIONS that they have gotten from them are ever worse than the burns. It's like flesh rotting disease. Like you'd do, I would think, almost anything to prevent getting to that stage! (Pamela)

These women were living examples of the effects of radiation that the other women who refused radiation had either witnessed or read about.

Tamoxifen

The women read that tamoxifen was not recommended for women who were pre-menopausal, and for tumors that were estrogen-negative. Therefore, they

became very confused when they were being offered tamoxifen and they fit into those two categories. Helga was not sure she wanted to remain on tamoxifen because it affected her stomach. Both Audrey and Bernice postponed taking tamoxifen for a month after being given the drug.

> When they gave it to me, I delayed for month, I didn't take it for a month after they gave it to me. And, I am still not sure if that was the right decision. So, I've been on it for three months now. (Audrey)

> I really do wonder if it's helping. And when I have my hot flashes, I really wonder. Do I really need to be experiencing this? (Bernice)

Tamoxifen was considered to be too great a risk by nine of the women. They commented that the daily intake of a drug for five years would interfere with their ability to return to 'normal'.

> This does not look like a healthy option for me either. There are too many long term risks. I was feeling, okay, best case scenario here is that I am going to be able to rid myself of whatever fragments of this cancer are still there. And go on to live a healthy normal life. And the tamoxifen is going to hold me into, or take me down another path which again, the compromises are not short term, but they could be long term quite serious. And so, I am not prepared to take that risk either. (Liz)

> Why should your life be in the toilet in anticipation of waiting for something else to happen. And it's a constant reminder! Every day you have to take this rotten little pill in case you get it back. (Pamela)

Four premenopausal women in this study who accepted prescribed therapies (ages 37-50) commented the impact of therapies on their sexual relations with their husbands. Carolyn and Faith complained that chemotherapy had a negative impact on their desire for sexual intercourse due to vaginal dryness and loss of libido. Audrey said that exhaustion from the radiation and subsequent depression affected her sexual relations with her husband. Kim believed that the

complementary medicine was responsible for reversing the negative effects of chemotherapy and returning her body to normal.

The women who accepted some of the adjuvant therapies had to contend with the side effects of the therapies on their bodies. The women who refused therapies made the decision that the risks outweighed the benefits. One hurdle that each woman had to deal with was the effect that breast cancer had on her mind.

Mind

For some women the idea of losing a breast carried with it emotional as well as physical scars. Many of the women talked about the sadness and fear that clung to them when they were first diagnosed. They felt as though it was happening to someone else and their confidence was shaken.

> He (friend) couldn't understand how the physical part is nothing. I mean they take the lump out, it's gone. They sew it up and that's a nice scar, it's healing. But, the mind part is just so huge! And how, until you have been there, nobody else understands! I mean, they think, it's gone, okay that's it, you're back to normal. It's fine. And, that's something that other people just really don't understand. (Irene)
>
> I wasn't having any more surgery (after the lumpectomy), I would not have it excised, I would not have my breast removed. And, I wasn't totally against having my breast removed, but the one thing I did find, is, I was having a really hard time coping with the scars (sadness). And I thought, "If I'm having trouble coping with this scar, to have another major one, a breast removal, I would probably have terrible depression, would have a really hard time with it." (Audrey)

> Some days I find it very depressing that it happened. It kind of knocks you for a loop. But I sometimes think, like, did it really happen? And then you look in the mirror, "Yeah, it did!" But it sometimes feels like it happened to somebody else. It was just something you had to take in your stride and let go. But psychologically, sometimes it's really depressing. (Carolyn)

An "emotional shift" occurs when surgery, chemotherapy, or radiation alters the women's physical appearance. Previously they had considered

themselves to be strong competent women: "I usually have ten balls in the air and they pretty much land where I anticipate they are going to land" (Faith). Now they have been thrown a life threatening diagnosis and their sadness is labeled as "anxiety". The women did not appreciate being told that they must "think positive" when they were feeling pathetic and lonely.

> How can I think positive when I have just had my breast lopped off, I am a young woman, I had beautiful long hair and now I am bald! I look like crap. I can't get the energy to formulate a thought, let alone get it out of my mouth, and you are telling me to think positive! (Ellen)

The women feel like they were carrying additional guilt for perpetuating a negative emotional environment that was deemed to be conducive to the growth of cancer cells.

While the loss of a breast is traumatic, a greater concern is the loss of one's life. There were two different perspectives concerning the potential threat of cancer, as depicted in Table 11. The women who focus on "life" do not view cancer as a "death sentence". They faced the initial shock of their breast cancer diagnosis and then they took charge of their lives.

Table 11: Life or Death

LIFE	DEATH
Not a death warrant (B)	Hit rock bottom (A)
Want to be a good statistic(C)	No Guarantees (D, E)
Isn't terminal (G)	Remove the breast so I can live (F)
It's about healing (L)	Something we can't control (H)
Don't even have cancer any more (after surgery) (M, P)	Do all this stuff, I don't want to die(I)
Not life threatening (Q)	Not scared to die (J)
Death is not the worst thing (R)	Fighting for my life (E)
	Desperate people dying (K)

> I didn't have any sense that this was a death warrant. This was just, my life was being threatened, because it was serious and it was a very disturbing, but it never felt like, suddenly, I was going to die! (Bernice)

Michele, Querida, and Roseanne all thought women take should take charge of their bodies and their health because "it's just cancer" and "it just takes time to heal and get on with life."

The opposite reaction is the fear of making the wrong decision that may shorten your life and bring death closer. They feel desperate and struggle with all the information as they search for a "magic bullet" that will cure them before it kills them. Ellen's fear came from choosing chemotherapy and Dominica's sadness came from terminating chemotherapy.

> You can have all the empathy in the world but you don't understand. And then you get pumped with chemo, which affects you because it gives you the insomnia, and now you're just a wreck. You are crying, you're depressed, and it's drug induced. Plus it's fear! I mean it's a near death experience. If it doesn't kill you it will cure you. I really, I used to wish that I would not wake up. It was awful. (Ellen)

> I'm just having a hard time going out of the sadness. I am not always thinking, "Oh God, now what am I going to do?" You know, and hoping you made the right decision. And every day you live by that decision. (Dominica)

The realization that there are no guarantees was devastating and caused the women to feel disconnected from a world that they used to control.

> Suddenly, here I am, a person who is very independent, asking my children to stay home because I am lonely. I have never been that way before. It was too devastating for me. … No matter what you do, there are no guarantees! (Dominica)

> I am stoic! Is that the word? I just keep working. You can overcome. However, I lost it with the breast cancer! … Then all of a sudden I lost connection! I lost a focus. My focus was gone. (Pamela)

> I thought that I would be okay, but I ended up breaking down! You know, like, I just thought, I am in control here. I have a handle on all this! But it's, I don't know, It's just. You think you do, and then somebody says something kind to you, and then you just, OOOH. (Querida)

The bodily changes and the emotional turmoil are only two sides of the triangle that encapsulates the women's personal stories. The third side goes beyond curing the body and reassuring the mind. The triangle is completed when the women find ways to "healing the spirit".

Spirit

Breast cancer challenged the women to examine where they were going with their lives before the diagnosis and where they are headed in the future. They talked about their purpose in life and the need to follow their hearts. Not all of the women thought initially that something good would come out of breast cancer and that there was wisdom to be gained from the experience. They were not even sure that life would continue. As time passed, their focus changed and they chose to live in the moment. Their words speak from their spirit.

"There were angels guiding me" (Audrey) and "if you choose to learn, you can take that wisdom to others" (Bernice). "Your whole outlook on everything changes" (Carolyn) and "each day is a gift" (Dominica). "I don't have the energy or time to waste on the small stuff, I just want to live" (Ellen). "I've got right now, today; I don't know about tomorrow." (Faith). "I felt much more spiritual through the experience" (Geneva), and "I've got a few more years of happiness with my grandchildren for which I am thankful" (Helga). "I went from almost a death sentence to elation" (Irene) and "it is going to affect my life forever!" (Jocelyn). "I was very successful, whatever that means; I've redefined

that, it meant absolutely nothing" (Kim). "I had faith that as far as I was concerned, this was not about saving my life, it was about healing" (Liz).

For many women their hearts were changed as they prayed for discernment. "I have come here for a reason, just let me know (God) what I am supposed to do" (Michele). "The spirituality is obviously key and helps me trust the process and live with the mystery" (Odette). "I was never afraid of death, I believe there is a time that we are here on earth and then a time that we go to the next place" (Pamela). "I thought the whole thing was a wake up call for me and it just really affirmed for me that I had all that strength" (Querida). "I take one day at a time and I try to get my body, mind, spirit all kind of in one piece again, instead of feeling kind of fragmented" (Roseanne). Amen.

Time to Make the Decision

There is one final consideration that all of women mentioned concerning the decision making process. Even though the decision involves a life threatening illness, all of the women agreed that they needed time to really look at all the resources, and to really look inside themselves. This is the advice the women gave after making their own decisions.

> Sit back and pretend it's somebody else. What are the different ways, the different things? The different treatments, weigh the different options you have. I don't care what method you go with, or what the end result is, in the back of your mind there's always that question about what happened to the other 15%? Sit down, and say, which way do I want to go? What does it mean to me? And then go from there inside. You have to make that decision. (Carolyn)

> Your head is spinning! You don't know whether you are coming or going. Just STOP and take a breath, A couple of weeks isn't going to make any difference. Their whole lives are in front of them. They are worried about themselves, their family, everything. Probably their job that they know

> they have to take time off. Explain to them that it would be good for them to take the time to just absorb it, talk to your family, talk to a counselor, talk to the cancer clinic. (Querida)

A quick decision, according to Irene, Liz, Bernice, and Faith, is based on fear. Fear that the cancer will metastasize within weeks. Fear that the oncologist will be angry if you do not start your therapy on the appointed date. Fear that you will appear indecisive and ignorant. Regardless of that fear, they believe that you should not be pushed to make a decision.

> Cause it isn't a heart attack. I know that there are some types of cancer that are very fast growing. And you don't have the time. And especially, all the conditions you know, if you were younger, if you were really sort of in your 20's or 30's and had something diffuse going on there. And you want to get done fast! You want to get on to it. So again, it was my individual situation. (Liz)

> It is way too rushed and I don't think it ever becomes a life and death situation that you never have the time to get the information. I think there's always time. Even, you know, if it's such a huge lump, that they have missed it and whatever, you know, they think it's stage 3 or 4 or whatever. I really think that there is time to get informed. And I think it is so unfortunate that they want to do things so quickly. And it just doesn't give you time to think about it, and to weigh your options. (Michele)

Now is the time and place to reveal the women's decisions.

Making a Decision "I Can Live With"

The Basic Social Process (BSP), as mentioned previously, must explain all variations in the problem being studied, predict behaviors, and show how these processes may evolve over time. Throughout this chapter the process of justifying the refusal of breast cancer therapies was examined from various angles in relation to the women's pre-established preference for prescribed adjuvant therapies and/or alternative therapies. The cross-tabulation of these two

portrayed in Figure 3, provides a conceptual model that will be used to analyze the variations in the decisions that the women in this study "could live with".

The completion of the decision making process will be described in relation to the four ways that the women justified their final decisions: 1) persuasion, 2) conviction, 3) modification, and 4) omission. The individual explanations will include the therapies that were refused and/or accepted, the reasons for the refusals, and the new options that were developed when the prescribed adjuvant therapies were modified or refused.

Figure 2: Cross-tabulation of Women's Therapy Choices

		Acceptance of Adjuvant Therapy	
		Yes	**No**
Acceptance of Alternative Therapy	**Yes**	**1) Persuasion** Agree to some of the prescribed therapy and complementary med	**2) Conviction** No Adjuvant therapy Only alternative interventions
	No	**3) Modification** Agree to some of the prescribed therapies and reject/modify others.	**4) Omission** Small Tumor Cancer Recurrence Co-morbidity Elderly

Persuasion

These women accepted some of the prescribed therapies and also chose alternative therapies (24%) (Table 12). All of the women had either university or college education. They all used 'visualization' as a technique to control stress that was the result of overbearing mothers, resentments towards husbands and

children, or demanding work situations. They used alternative medicine to detoxify their bodies and boost their immune systems in an effort to deal with environmental pollutants.

Table 12: Persuasion: Accepting Adjuvant and Alternative Therapies

Participant	Decision	Reasons For Refusing / Developing New Options
Bernice	Refused: Chemotherapy Radiation	Synchronicity and receiving answers from God, "You are well, you do not need chemo or radiation".
	Accepted: Tamoxifen	Her family convinced her to take tamoxifen. She changed her diet completely and used visualization and pray to heal.
Dominica	Refused: 5/6 Chemotherapy Radiation Tamoxifen	Started chemotherapy for her children and surgeon and terminated for her 'soul'. Switched to homeopathic medicine to deal with 'escapies' and 'offer a lifetime without being poisoned and burned'.
	Accepted: 1/6 Chemotherapy	Homeopathic and naturopathic treatments; Drastic diet change – vegan, no wheat, no sugar.
Kim	Refused: Tamoxifen	Control trial wanted to add tamoxifen after the original protocol was established. Tamoxifen increased risk of uterine cancer. She was pre-menopausal and not estrogen positive.
	Accepted: Chemotherapy	Accepted her husband's suggestion for alternative medicine. Spread sheet of alternative medications. Homeopathic medicine, QuiGong; meditation
Odette	Refused: Chemotherapy	She had seen other women in her religious community go through chemotherapy and she didn't think it was worth it for such a small tumor.
	Accepted: Radiation Tamoxifen	Continued with acupuncture and massage therapy.

While Bernice and Dominica preferred to use alternative therapies, they were persuaded by their children and physicians to try at least one of the prescribed therapies.

> One of the hard things is to go against what is the Western mode. Which is the medical mode! So you have to have pretty strong sense of yourself to say no to that and stand with what you believe. Knowing that there's risk, there's just plain risk. That's just the way it is! You know, either way you're at risk. (Bernice)

> When they took out 17 lymph nodes there were 13 that showed signs of cancer in them, she (surgeon) figured that some could have already got into the other parts of my body, that's why the chemotherapy or radiation was recommended. Right, I didn't object at the moment. I thought that trying to combine the both medicines could be a good thing, and that taking all the precautions of the natural medicine after the chemotherapy and applying my own knowledge afterwards would be enough. But in my own heart, I know that the chemotherapy, radiation, tamoxifen, or chemicals, drugs, is not the answer. That the answer comes from within. And, that you have to practice healthy living! (Dominica)

Kim's husband persuaded her to incorporate an extensive regimen of alternative therapies to complement the prescribed chemotherapy and radiation therapy. However, Kim was not convinced by the oncologist's statistics that tamoxifen was a safe risk for her.

> We go back, we do this test on the tumor. It is NOT progesterone or estrogen positive! And I am going, "Well FORGET IT!" I mean, you didn't even check that. You were going to give me this thing for 5 years, with all the risks that are associated with it, I am not going to take it! He says, "Well there is a good chance that you will get kicked off the trial!" I said, "I don't care! That's not a good enough reason for me to be taking this drug. So we had quite a bit of argument over that. And he finally said, "Fine. It's your choice. If that's what you choose." (Kim)

Odette and Bernice were both influenced by their religious persuasion when they refused chemotherapy: Odette witnessed the experiences of the women in her religious community and Bernice waited for God's guidance.

> Anything to do with an act of faith, is a risk. So is chemo! It's probably one of the riskiest things you'll ever do! Is to take chemo and radiation. Because, I mean, WE KNOW what it does to our body. And so you balance this risk against that risk, and you make the spiritual choice that's right for you. I just accept the risk. We actually are in this relationship, in this dialogue with God. Whether we choose some portion of the medical mode, or announce NO to the medical mode. Every decision that we make has a consequence. (Bernice)

> I know that in my own mind, I had dismissed the idea of the chemo, even before we had talked about it. Cause in a religious community you see a lot of women who go through it. And it is just not something I would choose to do at all.... So the sense of being able to realize that you and God are kind of creating this journey which you go through. And you don't do it alone! Helps you trust the process. (Odette)

Conviction

These women held firmly to their belief in alternative therapy and therefore refused all adjuvant therapies (24%) (Table 13). They thought that their breast cancer was triggered by hormonal imbalances due to late pregnancy and the use of birth control pills. Oppressive relationships with others, especially mothers and husbands, were also thought to have been contributing factors concerning their breast cancer.

Liz's conviction to her faith was similar to that which Bernice and Odette referred to in the previous section.

> The surgeon initially was really nervous about what I was talking about. And until we had enough conversations and I told him I was a minister and that I had faith and that as far as I was concerned, this was not about saving my life. It was about healing and if I was going to die, I wanted to die the healthiest corpse they had seen. But I didn't want to compromise this already compromised health system within me anymore. And that I just had this very strong feeling that chemotherapy would just do me in. And I didn't intend to spend a life being an invalid. So I wouldn't throw the dice and take my chances. And once he was clear that I was both well informed of the risks and the consequences, he was very co-operative. He said, "Okay. Let's do it." (Liz)

Irene and Michele had strong preferences for alternative medicine prior to their diagnosis of breast cancer and they were not convinced by probabilities of survival because they had seen their loved ones die after suffering through chemotherapy and radiation.

Table 13: Conviction for Alternative Therapy

Participant	Decision	Reasons for Refusing / Developing New Options
Irene	Refused: Chemotherapy Radiation Tamoxifen	She fainted in the radiation room and she thinks her body told her not to have radiation: Fear.
		Herbs and vitamins; acupuncture; detoxifying body; naturopathic medicine; positive affirmations
Liz	Refused: Chemotherapy Radiation Tamoxifen	Armed with statistics concerning risks and benefits, she listened then refused. Her compromised immune system didn't need more toxins. Tamoxifen has long term risks.
		Yoga, vegetarian diet, holisitic medicine, healing circle, meditation.
Michele	Refused: Chemotherapy Radiation Tamoxifen	Chemotherapy and radiation are too hard on the immune system.
		Whole body medicine: Chinese medicine; diet changes, exercise, homeopathic medicine, boosting immune system and detoxifying body.
Querida	Refused: Radiation	A gut feeling that the radiation wasn't going to do me any good and would compromise the reconstruction site.
		Herbs and vitamins

> How many people do you know did the radiation, did the chemo, did all that stuff, and they came out that they were going to die anyway! Right! So what the hell good did it do? You know, and they went through all that misery, for a 1 or 2% chance, greater chance of survival. (Irene)

> When I look back on it, I often think too, cause when we do other reading about it, we say, ladies that take chemo, their immune systems are so weak. That when they get the pneumonia, and if autopsies are done on a lot of these women, 40% of them have died of malnutrition, rather than the breast cancer. And so that, and I think back to my sister and I think, you know, those last three or four months, she just looked totally wasted. Maybe it wasn't so much the cancer, but what everything else had done to her previously. And she just couldn't get her body back on track. And so that was a real boost too, for us to decide not to do the chemo. (Michele)

Conviction comes from a firm belief that is deep inside these women. They know their own body, mind and spirit and they are not persuaded to go against their instincts.

> I just had a GUT FEELING that the radiation wasn't going to do me any good! That it was just some kind of extra insurance. And I just didn't really think that it was necessary. And I didn't think it was necessary to mess up my reconstruction. Because I had sort of made this promise to myself, you know, 6 months before, that, "Okay, I can do this because I can have the reconstruction and I can feel whole again afterwards!" And, you know, I really did think that it was only recommended as extra insurance. (Querida)

Modification

These women preferred prescribed therapies but they modified their treatment regimes due to the risks associated with the medical interventions (47%) (Table 14). Breast cancer was thought to be caused by flawed cells or hormonally altered cells. They believed that stress trigger the growth of cancer cells or compromised the body's immune system so that it could not eliminate cancerous cells. While they introduced herbs and vitamins, they did not seek out alternative therapists.

Carolyn and Ellen accepted the chemotherapy because they wanted to "kill the cancer cells". However, they were convinced that the side effects from

Table 14: Modification of Adjuvant Therapies

Participant	Decision	Reasons for Refusing/ Developing New Options
Audrey	Refused: Chemotherapy	Chemotherapy damages the heart and immune system that were already compromised by heart surgery.
	Accepted: Radiation/Tam	Convinced oncologists to give her radiation. Oncologist convinced her to have tamoxifen.
Carolyn	Refused: Tamoxifen	Conflicting medical recommendations concerning tamoxifen; fears concerning blood clotting and uterine cancer. No lymph nodes involvement.
	Accepted: Chemotherapy	Evista for her bones, and it may have some benefits for breast cancer too.
Ellen	Refused: Radiation Tamoxifen	Radiation causes cancer: "Cooks you from the inside out. May damage heart.
	Accepted: Chemotherapy	Complementary vitamins
Faith	Refused: 1/6 Chemo	Heart toxicity – terminated final chemo.
	Accepted: 5/6 Chemo Radiation/Tam	Stopped smoking and turned to spirituality.
Geneva	Refused: Chemotherapy Radiation	She didn't want her hair falling out and the memory of radiation damaging people's feet: her surgeon said radiation not really necessary.
	Accepted: Tamoxifen	No comment in this area.
Helga	Refused: Chemotherapy Radiation	GP and surgeon recommended she refuse radiation. Other people were fine without any therapies.
	Accepted: Tamoxifen	Calcium for her bones and moderation in all things
Jocelyn	Refused: Tamoxifen	Cannot take tamoxifen because she has 'reflex soleus dystrophy': lower quality of life.
	Accepted: Radiation	Diet changes, chanting, meditation.
Pamela	2/6 Radiation Tamoxifen	Radiation burns so modified radiation to 3wks. Terminated tamoxifen after 3 weeks versus 5 years due to leg cramps and nausea.
	Accepted: 4/6 radiation	Herbs and vitamins

tamoxifen and radiation therapy respectively were too severe and refused those therapies.

> The big thing that he (surgeon) said to me, I wouldn't have to have Tamoxifen, because I was really concerned about that and I said I didn't want to take it! … About the fourth treatment she (oncologist) mentioned that she'd like me to take tamoxifen. And then my husband and I discussed it and I said to him, "I'm not taking it." I said, "Side effects, family history. I'm not taking it." And then we told her that the surgeon said "No." So I said, "I don't want to do it", and she didn't feel that, being that my Dad had experienced blood clots, that it would create a problem. She said you don't know until you try it. But I didn't want to try it to find out. I just said "No." And she said, "Well, it's totally up to you". And then each time that I had to see her she mentioned it again and, finally at my last treatment I said, "No I'm not taking tamoxifen. I'll just take my chances." She said, I'd only have an 85% coverage with the treatment I took, the mastectomy and chemo, and I did All my chemo. (Carolyn)

> I refused radiation, because radiation to me, well first of all, radiation causes cancer. And I didn't want to be cooked from the inside out. Something about it really scared me. And I also know that there is permanent damage to your bones and to your lungs. And that in the future there can be some real damage. You know, osteoporosis, or just whatever. I just couldn't do it. So I received quite a bit of flack! Pressure from my GP, my oncologist, the radiation oncologist. You know, "You still have time, you still have time, you still can do it." But I didn't want to do it. I choose not to. They would have had to shoot me, drag my body there to zap it. … And I don't regret it. I never will regret it. Because if it come, back, it will come back. What I was saving radiation for is, say I get bone met's, I want to save it for the big guns for pain maintenance. (Ellen)

Although the women may have had strong justifications for refusing therapies, there were situations when the oncologists convinced the women to accept treatments that they were planning to refuse. As mentioned previously, Audrey was convinced by the persistence of the medical oncologist, who took an hour of her "valuable time" to persuade Audrey to take tamoxifen.

Faith accepted radiation therapy, tamoxifen, and all but one chemotherapy treatment. While she embraced the medical interventions, she personally

monitored the risks of the chemotherapy and terminated the chemotherapy when she experienced shortness of breath and twinges in her chest.

> After my last chemo, I went in to see them, the oncologist, and I just said to them, "I will not be having the last chemo treatment." And he said, "Oh." It was almost like he knew! But up until then they hadn't been believing me. 'I was anxious.' … Anyhow, they did a MUGA [MultiGated Blood-pool imaging] on me and I was at 51%, and it showed acute myocardial toxicity. And it was only after that report came in that everybody started to listen to me. (Faith)

Geneva and Helga accepted their surgeon's concern that the risks that accompanied chemotherapy and radiation outweighed the benefits, and they refused, regardless of their oncologist's suggestions. As stated earlier, they also accepted their surgeon's recommendations to take tamoxifen.

> I really didn't want radiation, because I used to have it on my feet all the time when I was getting shoes. You know how terrible that was on little children. A person can only stand so much radiation. (Geneva)

> I had an appointment at the cancer clinic with the oncologist and I said "No, everything I want is to take the tamoxifen, but I don't want any (other) treatment." So, then when I came home I felt, "Yes-No, to radiation." She suggested radiation. I wasn't quite sure. One day I wanted it, and then the next day I thought, "No, no I don't want it." After 2 weeks or so I decided, "No, I don't want any treatments." … Well, the doctor (oncologist) wasn't too happy that I didn't go along with her. I believe she thought that. And she said "So, anytime you need me or want me, I'm here, you know, make an appointment and come and see me." (Helga)

Jocelyn and Pamela both refused tamoxifen because they felt that their legs were already compromised and any increased risk of blood clots would be too dangerous.

> We talked a little bit about Tamoxifen. And I said, "I can't have Tamoxifen." So he said, "Why not?" And I said because I have RSD. "What's RSD?" Reflex soleus dystrophy. It is screamingly painful. Actually, my bone is porous on that side. I am going to walk out of here. I ain't going out of here in a wheelchair. Because, I don't think I could cope. (Jocelyn)

> I wasn't feeling that good taking tamoxifen, and I did have some leg, kind of aches and pains, similar to what I had before I had my varicose veins stripped! You know, it was like a deep bone. I thought, now let me see, "Nothing in the lymph nodes. I am going to do the radiation. My margins were clear. And like my quality of life is in 'the toilet'! Why should your life be in the toilet in anticipation of waiting for something else to happen! And it's a constant reminder! You know, every day you have to take this rotten little pill (tamoxifen) in case you get it back. (Pamela)

As mentioned in the section concerning husbands, Pamela also justified the reduction of her radiation therapy by two weeks because of the risk of severe radiation burns.

Omission

Roseanne was the only participant in this study who omitted all adjuvant therapies and who did not seek out an alternative therapist instead (Table 15).

> I left "The System!" (cancer clinic) Which was what I really was most concerned I didn't want to be part of! I didn't want to focus my life on cancer! I wanted to focus my life on being well! And so, for the most part, I don't even think about it, anymore! I wanted to very much put it behind me. Not that I am a denier! That is not what I am wanting to do. I am really wanting to move past it and to live in a way that hopefully will mean that it won't recur.... I never felt that this was sort of the focus of my life. I really feel that it's a finishing of something. It's the last stage of something. And it is DONE! It's finished! So, it was very easy for me to make that decision. (Roseanne)

Table 15: Omission of All Therapies

Participant	Refused Therapy	Reasons for Refusing/ Developing New Options
Roseanne	Refused: Radiation	This thing is finished; therefore, she doesn't need any more therapy for the small tumor.
		Previously practiced meditation and went for acupuncture and massage therapy.

There were two other women who were over 80 years of age who were not included in this study, but they provided explanations for refusing all adjuvant

therapies. Sage will be celebrating her 90th birthday soon and she said that her tumor was so tiny that she could not even feel it. She decided to have a mastectomy and "leave it at that" so that she could maintain her excellent quality of life. Theresa has multiple sclerosis and her tumor is almost as large as her breasts. Her greatest concern was compromising her arms because she needs her arms to maneuver her wheelchair. Therefore, she refused surgery and adjuvant therapy and does not use alternative therapies.

Summary of Health Care Providers' Reactions

Patient-health care provider communication is a critical dimension of health care. Despite this understanding, communication between the women and their health care providers was often problematic. The positive and negative reactions of health care providers are summarized in Table 16. The fact that only two women did not experience a negative reaction from a surgeon and/or an oncologist demonstrates that refusal of adjuvant therapies is not an expected response within the health care system. Research concerning social constructions of breast cancer acknowledges the fact that "compliance gains approval" (Thorne & Murray, 2000). In this section concerning physician's responses, reactions that were quoted previously will be referred to in more general terms to avoid repetition.

Beginning with the positive responses, Odette felt "free to make the choices" that she made because her radiation oncologist told her "It's your body". Geneva completely bypassed the return visit to her oncologist because her

surgeon wrote the prescription for tamoxifen and she picked up her medication from the cancer clinic.

> My doctor (her surgeon) really explained things well and gave me a choice and choices. He didn't push me in any way to decide what I should be doing. ... I guess he knew that I was happy and things were all right. I didn't really need an oncologist. He was very nice. (Geneva)

Table 16: Positive and Negative Reactions of Health Care Providers

Participant	GP		Surgeon		Med Oncol		Rad Oncol		Alternative	
Reaction	+	-	+	-	+	-	+	-	+	-
Audrey			1			2		2		
Bernice					4	3	1		1	
Carolyn	1					2				
Dominica			4	3					1	2
Ellen		2				2		2		2
Faith	1					2				
Geneva	1		1							
Helga	1		1					2		
Irene				2				2		
Jocelyn				2	1			2		
Kim		2	1			2			1	
Liz	1		1		1			2	1	
Michele				2		2			1	
Odette							1			
Pamela	1		4	3				2		
Querida	1		1	2						
Roseanne								2		

1 = positive reaction
2 = negative reaction
3 = negative experience with first physician
4 = positive experience with second physician

As mentioned previously, Audrey, Carolyn, Ellen, and Jocelyn, were told by their oncologists, on several occasions, that there was still time to change the decisions. Bernice's oncologist confronted her and asked her if she was "crazy". Fortunately a second oncologist interceded to be sure that she was informed and

then he wished her well. The oncologist and the oncology nurse were convinced that Faith was just anxious until the final MUGA revealed that she had heart toxicity and the chemotherapy was terminated. Kim's oncologist warned her that she would be kicked off the control trial if she refused tamoxifen. When Kim decided she could "live with her choice" but not with the risks of tamoxifen, the oncologist continued to monitor her progress. Michele and her husband were told she would die if she refused all therapies. She is currently finishing her Master's degree, almost two years after her diagnosis.

There were several women who reported that the radiation oncologist was "not too happy to begin with", but later extended an open invitation to return anytime.

> She (radiation oncologist) said, "What do you know about breast cancer?" And I said, 'Well, probably not as much as you, but I have to tell you how I feel! Which is, that this thing is finished! I don't need anything more! And I don't want the radiation!" … There was a little bit of an edge! But she was the one that said, "Come back if you need us." So, she might have just had that kind of immediate response, "Well, you know, who do you think you are?" But it didn't last! (Roseanne)

There were fewer negative experiences involving surgeons, family doctors, and alternative therapists because they were not as challenged by the women's decisions concerning adjuvant therapies. For example, Irene and Jocelyn were upset because of the effect of the surgery on their arms, not because of their surgeon's response to their refusal of adjuvant therapies. Similarly, Querida did not appreciate that her surgeon did not remove her lymph nodes, so she found another surgeon to perform that surgery. Overall, the women commented on the

support that they received from surgeons, family doctors, and alternative therapist, as mentioned earlier.

> My surgeon, took a marvelous approach, I think. He clearly gave me the straight goods as far as the medical protocol was concerned. And he made sure I understood it. And I was able to come back and say, "Yes I understand that's the protocol. But I also understand that here are the risks." So when he knew that I'd heard him, and he knew that I knew something about what we were talking about, then he was able to set that all aside and say, "Okay, so what is it that you want to do?" You know, I think there's the two way street there. They have to, it would be irresponsible of them to let some woman come in and howl on their table about not wanting to lose their beautiful breast or whatever, and say, "Well okay, we won't take it off!" You know, when that obviously was what they felt was what had to happen. They can't do that. (Liz)

The women in this study recognized that there were physicians who used control, anger and intimidation to influence the women's decisions. There were also physicians who engaged in a collaborative relationship and were willing to hear and respect the women's choices. The women preferred the later.

Summary

The objective of this chapter was to describe the intricate justification process that women went through so that they could live with their decisions concerning breast cancer therapies. Information was gathered, reviewed, internalized and if the women thought it was necessary, they spiraled through that process again. This justification process affected others within the health care system, family, and community. During the examination of the women's decision making processes concerning adjuvant breast cancer therapies, four justification styles were identified: 1) persuasion, 2) conviction, 3) modification, and 4) omission. The next chapter will discuss the data analyzed in this chapter with

respect to the existing literature and the justification process will be reviewed within an ecological framework.

VI. DISCUSSION

The women embarked on a journey through an integrative ecological system as they completed their personal breast cancer research, communicated their choices concerning prescribed therapies, and then followed through with their final decisions. These women established control over their lives by searching for knowledge from their internal and external environments. In this chapter the women's decision making process will be described in relation to the literature. First, the relationship between the persuasion styles discovered in this study and the existing decision making theories will be examined. Second, studies related to the internal environment including the physiological and psychological factors involved in decision making will be described. Finally, studies related to the external environment will be explored: relational factors involving the family and contextual factors relating to the investigation of current information, interactions with health care providers, informed consent, and the socio-political environment.

The Human Ecological Framework

Human ecological theory attends to humans as biological and social beings, interacting with their environment. A human ecological perspective allows for the complexity of the data that women provided in their explanations concerning their engagement in the decision making process and the significance of the interrelation of internal and external environments that influenced that process. The women who have been diagnosed with breast cancer were trying to

establish control over their lives and environments by searching for knowledge from many different external sources that would fill in the information gaps and resolve their internal dilemmas (Appendix I).

The basis for this grounded theory research is symbolic interaction, which Denzin and Lincoln (1994) explain is the study of intersections of interactions, biography, and social structure in a particular historic moment. The women responded to perceptions, interpreted events, and were governed by the organizing tendencies of human interaction and human language (Gilligan, 1995). Human ecologists research the way humans respond to the forces and counter-forces that impinge on their capacity to become fully functioning (Westney et al., 1988). The women were able to determine their therapeutic interventions because they possessed the ability to examine possible courses of action and compare each potential action with the consequences of that action. In the next section, the preference styles that reflected the women in this study will be compared with the existing literature concerning women's courses of action.

Decision Making Theories

The women in this study actively modified or refused the recommendations of the oncologists. They wanted a substantial degree of involvement in making decisions about their treatment for breast cancer, preferring either active or collaborative decisional roles. This high preference for involvement occurred regardless of age and educational level. This finding is consistent with Degner et al's (1997) Canadian study determining the high levels of preference for involvement in decision making by women who had breast

cancer. In contrast, Beaver et al.'s (1996) earlier study of British women found that only 20% of the newly diagnosed women wanted to play an active role and 28% wanted to share in the decision making, leaving 52% who wanted to play a passive role. Their suggestion was that cancer diagnosis has a disabling effect on preferences to participate in decisions concerning treatment. Degner et al's suggested that more recently diagnosed women might be experiencing a change in the patterns of communication within the health care profession. It may be that the women interviewed in this study fit within the 20% of women who wanted to play an active role and the 28% who preferred to share in the decision making.

The decision making behaviors described in this study provide a basis for understanding the decision process of women who refused adjuvant therapies. Each decision making style has unique characteristics that suggest the need for more individualized interventions and support for women making difficult decisions. Four decision making/justification styles were identified in this study in relation to the women's pre-established preferences along a continuum between traditional medicine and alternative medicine: 1) conviction 2) persuasion, 3) modification, and 4) omission. The *conviction* style involves choosing alternative medicine exclusively. The *persuasion* style used a combination of traditional medical interventions and alternative medicine. The *modification* style entails a preference for the traditional medical therapies and not alternative therapies. The *omission* style involves the refusal of all adjuvant therapies and not seeking out alternative practitioners.

Conviction

Women who expressed that they had a "conviction" about using alternative medicine prior to their diagnosis did not choose any traditional biomedical therapies other than surgery (24%). They were firm in their resolve to bring their bodies back to a state of wholeness by creating an environment inside and outside their bodies that was not conducive to the growth of cancer cells. While this may seem like a radical decision, Monson and Harwood (1998) revealed that 70% of women with early stage breast cancer will be cured by local surgical treatment alone.

The women's conviction for alternative medicine prior to their diagnosis confirms Adler's (1999) study: Sixty-nine percent of the 86 women in her study who had received a histological diagnosis of breast cancer had used complementary and alternative medicine (CAM) before they were aware of their breast cancer diagnosis. Swanson (1998) described how breast cancer patients who used CAM instead of tamoxifen did so because they hated the sense of losing control over their lives. The women in this study defended their preference for CAM, unlike the people who sought CAM in Eisenberg et al's (1993) study. Their findings revealed that 70% of those people who sought CAM therapies chose not to inform their physicians.

The women who had a conviction about CAM fit the coping pattern of "vigilance" described by Janis and Mann (1977), where the decision-maker meets all of the criteria for quality decision making. They actively searched for information and advice and they appeared to have realistic consideration for the

negative as well as the positive aspects of their decision. The women shared elaborate therapy regimens and contingency plans with their healthcare providers, husbands and other family members. They had clear objectives concerning their active participation in the healthcare decision and long term commitments to elaborate treatment regimens. They appeared to have reviewed and verified the steps that lead them to their decision and continued to educate themselves concerning the therapies they were following.

When Reaby (1998) studied women who chose a mastectomy as their surgical treatment of breast cancer, none of the women used the coping pattern of vigilance. In contrast, 15% of decision-makers in Pierce's (1993) study used a vigilant approach to decision making. Pierce referred to women who used the vigilant decision style as "deliberators": they expressed a personal responsibility for making a quality decision more purposefully than the "deferrers" (41%), who frequently selected the alternative recommended by the physician, or "delayers" (44%), who compared options until one option clearly dominated. The one huge difference between participants who use the "deliberator" decision style versus the "conviction" style in this study was that deliberators experienced a lingering uncertainty about the eventual outcome and anticipated that some time in the future they might regret their choice. The women who used the conviction style to make their decisions felt that they were in "control" of their health care.

Persuasion

The uncertainty of Pierce's 'deliberator' decision style does apply to the women in this study who used a "persuasion" approach to their decisions (24%).

These women accepted some of the prescribed therapies and also chose alternative therapies. They were persuaded by family or health care providers to accept therapies that they were not initially intending to accept, which led to internal conflict and concern about future regrets. As in previous studies, the women felt a connection and commitment to the individuals that convinced them to combine adjuvant therapies with alternative therapies (Monson & Harwood, 1998). The fact that they compromised their choices to satisfy their husbands, children, or health care providers, did not in any way stop them from being diligent and decisive in their search for accurate information, but it did shift the locus of control away from the women.

All of the women who used the "conviction" style, and all but one of the women who used the "persuasion" style achieved university degrees, which agrees with Montbriand's (1994) findings that higher education level is one of the characteristics of people choosing CAM. All of the women in both of these categories would fit into the "monitoring style of coping with cancer" identified by Miller (1995). These women desired large volumes of information and used that information to execute instrumental actions. However, Miller also stated that high monitors were more likely to yield control to another, more competent individual. In this study, the women in the conviction group felt that they were competent decision-makers and the women in the persuasion group were persuaded for personal/familial reasons, not due to the competence of another individual.

Modification

The majority of the women in this study used "modification" as a strategy for making their decision (47%). While these women preferred the traditional medical interventions, they investigated the risks and benefits of all the prescribed therapies, and then modified the oncologists' recommendations due to the risks involved with the therapies. They either had strong convictions against certain therapies prior to the consultation with the oncologist, or they gathered information after their consultation and on the return visit explained to the oncologists that the risks of the therapies were too severe. The three women who terminated their adjuvant therapies researched the side effects that they were experiencing, decided that the risks to their survival were too great to continue with the adjuvant therapies. Siminoff and Fetting, (1991) also suggested that the more patients knew and the less sure the physician explanation of risks appeared, the more likely patients were to diverge from treatment recommendations.

The women stated that the side effects of the treatment they were refusing to be more probable and more severe than the recommended therapies that they accepted. When the women sought a second opinion, they shifted their trust and gave the control over the decision to the second health care providers and away from the original oncologists. When the women told their oncologists that they would not accept their treatment recommendations, the oncologists used more specific explanations concerning treatment benefits in an attempt to convince the women. Siminoff and Fetting (1991) also found that the "non-acceptor" patients in their study rated the first physicians' treatment recommendations as less strong

than the subsequent opinions of other physicians they consulted. However, it should be noted that only 3% of Siminoff's and Fetting's patients chose not to take any of the possible treatments recommended. Rather, patients were divided between taking less risky treatments (in terms of side effects) (55%) versus potentially more effective but riskier treatments (45%). Once again, the lack of patient participation in the decision process was attributed to the life-threatening nature of cancer, the complexity of the treatment information, and patients feeling compelled to make their decision quickly (Siminoff and Fetting, 1991).

This confirms the unique nature of the women in this study who were actively participating in the decision process. Also, the women who felt they made hasty decisions when they initially accepted adjuvant therapies, began to examine the literature concerning the side effects that they were experiencing, and decided to terminate therapies that they considered too risky. In this manner they felt that they regained control of their health care.

Omission

There was only one woman who refused all adjuvant and did not seek alternative therapists. She was in her 60's and planned to regain control of her life and put the whole incident of breast cancer behind her. She believed that the surgeon had removed all the cancer during the lumpectomy, especially since the tumor was small and there was no lymph node involvement. Other women who may also have opted out of all therapies include the two groups that were excluded from this study: women over 70 and women who had co-morbidities. According to the literature, older women place a greater value on their quality of

life and they are less likely to choose therapies with side effects, regardless of the possibility of increased survival rates (Hebert-Croteau et al., 1999; Lindley et al., 1998). Women over 80 years were more likely to have adjuvant treatments and dissection of the axillary nodes omitted from the list of therapeutic options, regardless of comorbidities, physical functioning, or women's treatment preferences (Chung et al., 1996; Mandelblatt et al., 2000).

Internal Environment

The woman's internal environment includes the physiological factors that affect the body, and the psychological factors that affect the mind and spirit. The women searched for explanations by learning about their own human biology and examining their lifestyles. The internal dialogue that occurred within a woman's mind and spirit included 1) remembering the cancer experiences of significant others, and 2) speculating on the causes of breast cancer.

Physiological Factors

The discovery of a breast lump was the beginning of the decision making process for the women. Twelve of the seventeen women found their own breast lumps, which supports the finding that over 70% of breast lumps are still detected by women themselves rather than by screening programs (Friedman, Nelson, Webb, Hoffman, & Baer, 1994). Three of the women experienced false-negative mammograms, and one woman's physician found the breast lump and insisted on an immediate core biopsy. Therefore, the women felt that they were in control of determining their healthcare, and they were skeptical of the value of

mammography as a screening tool (Burman, Taplin, Herta, & Elmore, 1999; Pellissier & Venta, 1996).

Their first decision women had to make concerned the choice between a mastectomy or a lumpectomy and radiation, which may provide the same probability of survival with less invasion to their body. The women had pre-established preferences along a continuum between prescribed therapies and alternative therapies. The women who preferred traditional medical interventions accepted the surgeon's suggestion concerning a mastectomy or lumpectomy. The women who preferred alternative therapies made the investment of time to seek out additional information rather than choosing immediate surgical removal of the breast lump. However, all of the women in this study expressed a strong preference for knowing the choices and participating in the patient-physician consultation. Studies support the need for physicians to provide quality information (Fallowfield, 1997). In the study by Protiere et al. (2000), the majority (79%) of women supported a shared decision making model as their ideal.

All of the women in this study made it clear that they thought it was essential to remove the cancerous tumor from their bodies, and they were satisfied with their surgery, whether they chose to have mastectomies or lumpectomies. Weiss et al. (1996) were astonished when they found that <2% of women would have retrospectively preferred a different surgical treatment, and this did not vary whether the women had chosen mastectomy or breast conservation. Four women chose to have breast reconstruction. They expressed similar desires to those in

another study: breast reconstruction allowed women to restore a sense of balance, and maintain a lifestyle and an image that is an important part of their feelings of being a woman (Contant, van Wersch, Wiggers, Wai, & van Geel, 2000).

The next decision involved a consultation appointment with the oncologists, where the risks and benefits of chemotherapy, radiation therapy, and/or hormone therapy (tamoxifen) were provided. While women were open to the information, they were also concerned that chemotherapy damaged women's hearts and internal organs and caused immediate menopause in pre-menopausal women (Levitt & Kennedy, 1998). As in other studies, women who experienced or witnessed radiation burns wondered about the internal damage to their bones and hearts (Sherwin, 1998). Women commented on how tamoxifen was being recommended to them even though they were premenopausal prior to chemotherapy and whose tumors were estrogen negative, which was contradictory to the literature concerning the drug (Rutqvist, 1998). The women were given the responsibility of making a decision concerning therapies that would have a physiological impact on them.

Lifestyle is connected to the personal behaviors that are the physiological results of the internal processes that the women went through as they established treatment preferences. Sherwin (1996) argued that women are held personally responsible for their breast cancer because of their lifestyle choices.

> Cancer is usually addressed as a disease of the individual, where individuals are expected to take responsibility for reducing their personal risks, and, if they do end up contracting the illness, they must turn to

> technological experts for help. The burden of both prevention and treatment rests with the individual, and each person learns to be personally afraid of cancer. (p. 194)

All of the women felt responsible for decreasing their chance of having a recurrence of cancer. Their awareness increased concerning the fact that smoking, high-fat diet, and/or alcohol and drug usage, may have compromised their immune systems or damaged their cells. They reported using dietary supplements, vitamin supplements and/or herbal remedies as a preventive measure. This is far greater than the American national survey that reported that forty-two percent of adults used complementary and/or alternative medicine in the previous year (Eisenberg et al., 1993).

The women who selected alternative therapies used different language from the women who preferred traditional therapies. They said that the alternative therapists worked on getting the whole body back to health: Their focus was on wellness, healing, and boosting the immune system. Lifestyle changes included drastically altering their diets by cutting out fats, dairy products, meats, and refined foods. They added dietary supplements, herbs, flax seed oil, and other self-medications suggested by a homeopath, holistic doctor, naturopath, or health food store. Spiritual practices, such as Reiki, Qi Gong, and healing prayer were carried out. The women tried to manage the stress in their lives by going for acupuncture and massage, and changing careers. They were rebalancing, cleansing and detoxifying. The women were motivated to regain control over their lives, or to attain control for the first time.

Psychological Factors

The 'body, mind, and spirit' are all affected by the woman's decision concerning her breast cancer treatments. The information a woman received when she was newly diagnosed with breast cancer was both unfamiliar and overwhelming and left her mind in a state of cognitive confusion (Nugent, 1995). While all of the women felt sad, several women felt that their depression affected their ability to 'think positive'. Other studies concerning women with breast cancer reported similar levels of anxiety and depression (Dowsett et al., 2000; Stanton et al., 1998). While half of the women focused on bringing their bodies back to a state of health, the other half struggled with the probability of death and the loss of control over their bodies. Jevne and Miller (1999) found that uncertainty and captivity lead to feelings of hopelessness:

> With uncertainty we fear that things will change in some way we do not want. In captivity we fear that some things will not change as we feel they need to. In both cases we seem to have lost control of our future. (p. 9)

All of the women recognized that they had to be careful to not let their fears lead them to make hasty decisions. Despite their fears, the women continued to search for the truth and moved forward into the uncharted future. They remembered past cancer experiences and speculated on the causes of their breast cancer.

Remembering Cancer Experiences

When the women recalled their past experiences with cancer, their greatest fear was that history would repeat itself, and that aggressive adjuvant therapies would rob them of any remaining quality of life, as it had done for their family

and friends. Pierce (1996) found that the memory of a particular illness on a family member or close friend profoundly confirms for patients that certain alternatives are unthinkable. The women in this study feared that their children would witness their death, just as several of the women had experienced when they were young. The women who had recently lost a sister or sister-in-law to cancer tried to keep their families informed of all their decisions to reduce their anxiety. Existing studies confirm that women wanted to retain their children's trust and help to alleviate children's fears concerning their mother's changed appearance or the possibility of death (Barnes et al., 2000).

The positive recollections about family members that survived cancer provided reassurance for the women who recognized that they too might live a full life after cancer. Since they wanted to emulate these success stories, eleven women chose a mastectomy instead of a lumpectomy and radiation therapy. Reaby (1998) found that 34% of the participants rejected the option of breast conserving surgery because they believed that mastectomy was the only effective way to rid themselves of cancer, and they perceived that mastectomy was the preference of their surgeons and their families. Reaby also found that the women who were not offered lumpectomy (66%) did not seek a rationale for being given a mastectomy. Past cancer practices may be influencing the women, their physicians, and their support systems.

Speculating on the Causes

The women speculated on what caused their bodies cells to become cancerous. Their perceptions of the causes of their breast cancer will be discussed in relation to their preference styles.

Conviction Style

The women who had a 'conviction' about alternative therapies emphasized the need to boost their immune systems in order to bring the 'body, mind and spirit' back into balance. They believed that all people have mutated cells due to toxic environments, both internal and external, which compromise the person's ability to control the growth of the cancer cells. Hormonal imbalances due to late pregnancy and the use of birth control pills were thought to trigger the growth of breast cancer. Their experiences of being in control of bringing their bodies back to a state of health supports Nugent's (1995) theory that affirming "self" through mobilizing inner strength creates a sense of success.

Oppressive relationships with others, especially with mothers and husbands, were considered by these women to have a negative affect on their bodies, mind and spirits. According to Bubolz and Sontag (1993), "decision making is the central control process in families that directs actions for attaining individual and family goals" (p. 426). During the decision making process, the women who used a conviction style felt empowered when they followed their goals and refused to be controlled by others that had directed their actions in the past.

Persuasion Style

The women who were persuaded to combine the alternative medicine with at least a portion of the prescribed adjuvant therapies, talked about the "cancer personality" that is mentioned in Bernie Siegel's work (Siegel, 1986). The premise is that feelings are chemical, and if a person does not deal with their feelings, the body receives a "die" message. Therefore, these women all used "visualization" as a technique for creating a vivid mental image of happiness to gain control over the images of their overbearing mothers, the anger with their husband and children, or the stressful demands of work. They also used alternative medicine to rid their bodies of environmental toxins that they believe everyone has to deal with because pollution is beyond their control.

Modification Style

The women who 'modified' the oncologist's suggestions concerning adjuvant therapies did not seek out alternative therapists. Breast cancer was more narrowly classified as a disease caused by genetically flawed cells or hormonally altered cells. Stress was thought to either trigger the cells or compromise the immune system so that the body could not eliminate the cancerous cells. Therefore, the preferred treatments included interventions aimed at altering the biological structure of the cancer cells either with chemicals or radiation.

The women modified their prescribed treatment regimens because they believed that the risks of the adjuvant therapies outweighed the potential threat of a recurrence of cancer. However, the actions of the women who used a modification style were in agreement with previous studies concerning women's

need to accept some form of medical intervention in order to kill any remaining cancer cells and help them handle their feelings of helplessness (Jansen et al., 2001).

The women in this study were not willing to go as far as 57% of the participants in a study by Palda, Llewellyn-Thomas, Mackenzie, Pritchard, and Naylor (1997): their participants were willing to accept post-operative radiotherapy for zero benefit. Nor would they agree with the chemotherapy patients (40%) in Jansen et al.'s study who said they would accept chemotherapy if it had no clinical benefit at all. Instead, they followed the pattern described by Stanton et al. (1998) who stated that the more the women perceived that the outcomes violated their original expectancies about procedural benefits, the greater the likelihood of adjustment difficulty over time. However, the women in this study adjusted to the perceived discrepancies by terminating the therapies that conflicted with their original expectations, thereby reducing future regrets.

Omission Style

The one woman who omitted all adjuvant therapies thought that her cancer was caused by a bad situation that she had recently left. She felt that removing the tumor and leaving the bad situation would significantly reduce the chance of a recurrence and she decided to continue living life in a positive and healthy fashion versus accepting radiation and tamoxifen.

External Environment

The external investigation includes 1) relational factors that involved the family, and 2) contextual factors that involved the investigation of current information, health care providers, informed consent, and socio-political issues.

Relational Factors

Family provides a set of relationships and a space, that creates an environment within which the social, psychological, physical and economic needs of individuals are constantly interacting (Badir, 1993). Several studies mention the familiar web of interdependence between the economic, nurturance and socialization functions that exist within a person's family and community (Badir, 1993; McIntosh, 1985). The relations that had the greatest influence on the women's decisions include those with husbands and children. Mothers and sisters played a supportive role rather than an informative role.

Husbands

Sickness may drastically alter usual family roles and behavior patterns, and the needs and expectations of family members may be different from those of the patient (Shands, Lewis, & Zahlis, 2000). Husbands had a difficult time emotionally dealing with their wives' illness. Therefore, it has been argued that the spouses of individuals with cancer have substantial information needs (Meissner, Anderson, & Odenkirchen, 1990). Spouses expressed their pre-established preferences for traditional medical therapies and/or alternative therapies. Five husbands shared the same preference style as their wives, so the women felt supported and they presented their decisions jointly to the oncologists.

included three husbands who shared their wives' preferences for alternative therapies. Lichtman, Taylor, and Wood (1987) found that positive spousal support reduced psychological distress among women with breast cancer.

There were six husbands who did not share their wives' therapeutic preferences, which resulted in conflict. These women described themselves as "the risk takers" and their husbands as "compliant patients". They attempted to convince their spouses, either through documentation or meetings with other health care specialists, that the decision they preferred was reasonable. Four of the "compliant" husbands were convinced, and when they "got on board", they became quite assertive in defense of "their decision". The two unconvinced husbands ended up convincing their wives to default to their husband's choices and accept the adjuvant therapy that the women were originally planning to refuse. The women admitted that denying themselves of their choice was very frustrating and they felt "unsure of his choice" when they were having their chemotherapy treatments or taking the tamoxifen. Communication problems among couples who held discrepant views has been reported in the previous studies (Hilton, 1996).

Spouses may worry about the long-term effects of the patient's disability on critical aspects of the marital relationships, including sexual relations. Several studies indicated that women who have received chemotherapy are especially susceptible to adverse changes in their current sexual functioning (Dunn & Steginga, 2000; Young-McCaughan, 1996). Of the three women in this study who accepted chemotherapy (ages 37-48), two complained that the side effects

dramatically changed their desire for sex. One woman believed that the complementary medicine was responsible for reversing the negative effects and returning her body and sexual desires to "normal".

Children

The women's reactions towards their children were greatly dependent upon the children's ages, which ranged from 2 to 45 years. Previous studies have shown that younger women with breast cancer experience greater unmet needs, unhappiness and more distress concerning family matters (Siegel et al., 1999; Stanton et al., 1998). Eight women expressed a need to "be there" for their young children and teenagers, not only in the present as a nurturing parent, but also in the future to watch their children achieve their life goals. The mothers often shifted their concern away from themselves and tried to maintain some level of normality. Hilton (1996) described how individuals use strategies to retain normalcy: they minimize the effects of cancer while still recognizing the seriousness of the illness and its threat to life. Regardless of women's attempts to maintain the status quo, breast cancer drastically alters the usual family roles and maternal behavior patterns (Shands et al., 2000). Four women expressed guilt and sadness that their teenage children had to take over household responsibilities at a time when they were worried about the possibility of losing their mother.

Young adults, especially the female children, recognized their own increased risk of cancer. Chalmers, Thomas, and Degner (1996) argued that women with breast cancer were the most important sources of information concerning breast cancer for their daughters. Older adult children participated in

the information search. Once again, conflict would develop when the older children's preference styles conflicted with their mother's decision. When the women found themselves choosing tamoxifen to placate their children, this created conflict within the mother who felt that she did not have the freedom to choose her own destiny. The four women who were 60 years of age or older did not feel a need to accept or solicit input from their adult children, and they appreciated this autonomy.

Mothers and Sisters

Mothers of the women in this study reacted in one of three ways. The younger women's mothers were judgmental of their daughters' choices and provided unsolicited advice. The older mothers were either worried and offered sympathy or were supportive and empathetic. The latter response was the most appreciated and helped to "keep the women strong". There were occasions when the women told their family members very little in order to protect themselves from unsolicited advice and shelter their family members from further anxiety. Several studies also found that women with breast cancer said they did not discuss their concerns with their family members in an effort to reduce their fears (Carlsson & Hamrin, 1994; Ellers, 1993).

All but one of the sisters of the participants expressed confidence in the women's decisions and played a supportive role. The women deemed themselves responsible for bringing the burden of cancer into their sisters' lives. Love (2000) commented on how irrational it is for women to blame themselves for getting breast cancer and for feeling responsible for burdening their family members with

the reality of breast cancer. A positive ramification of the women's breast cancer experience is the influence they have on their sisters to be more diligent about early detection and prevention of breast cancer. Three sisters who witnessed the women's successes chose the same preference style when they found a breast lump. This confirms that the family is a key source of many learned values, beliefs, and behaviors that influence a woman's understanding of herself (Bubolz & Sontag, 1993).

Two women had sisters who went through breast cancer before they were diagnosed: one sister accepted all prescribed therapies and still passed away, so the woman subsequently refused all adjuvant therapies. The second woman's sister survived with just a mastectomy, so the woman experienced conflict when her surgeon convinced her to accept tamoxifen after her mastectomy. Several women stated that if you want to see a demonstration of supportive sisters, go to one of the breast cancer fundraising walks/runs.

Support from the family and community goes towards the women, and their experiences are reflected back to the supportive people. The women who had breast cancer learned so much and they in turn educated their families, friends, and other women who discovered that they had breast cancer. This sharing helps people cope with the uncertainly and loneliness of the disease (Jevne & Miller, 1999). The women benefit from sharing their new knowledge and they help to alleviate the fear and ignorance that may exist in those around them.

Contextual Factors

The community has its own set of values, standards, and support systems that influence the individuals within that community. Human ecology reinforces our awareness that we live within strongly interconnected communities (Visvader, 1986). During their struggle to survive and maintain a sense of well-being, the women relied on "civic" communities for social support: health care centers, support groups, their workplace, and so on. Studies show that civic cooperation and social integration are necessary to counter the social isolation that accompanies serious illnesses (Halldorsdottir & Hamrin, 1996; Polk, 1995). The communities are the arena for public participation in decision making, and this begins with individuals who seek out information, interact with individuals, and make decisions within a larger community.

Investigating Current Information

After the breast cancer diagnosis and surgery, the women had consultation appointments with their surgeons and/or oncologists. There were several limitations in the initial medical consultations: 1) limited comprehension at a time when the woman was feeling overwhelmed; 2) postponement of referral to a specialist/oncologist until the actual consultation at the cancer clinic; and 3) concern that the information at the cancer clinic would be biased. The women supplemented the physicians' information from several different sources. The percentage of women using the various information sources was as follows: reading material (94%) including popular and biomedical discourse, other women who have experienced breast cancer (88%), second opinions from health care

providers (88%), the Internet (50%), and videos (1%). According to Pierce (1996), supportive or consistent information reduced conflict for women who were deciding on breast cancer treatment. In order to reduce the conflict associated with non-supportive or inconsistent information, the women would continue to search for equally reputable pieces of supportive information.

Deciphering the scientific information about breast cancer was equivalent to learning a new language. For many of the women, the scientific information was housed in a location that was not accessible to them (Ashbury & Tobin, 1997). The local libraries were important sources of information concerning the risks and benefits of adjuvant therapies. This places a huge responsibility on this public service to provide current, evidence based literature. Palys (1992) called knowledge a social product, and the choices librarians make concerning what is available within a public library is governed by a group who has the power to decide what is relevant to know about breast cancer.

Five of the women, who all have university education, mentioned returning to the original articles, the scientific journals, or reputable sources. Pierce (1993) stated that women who perceived there would be conflict concerning their decisions seemed to be inspired to seek higher volumes of information. Six women who prefer alternative medicine searched through books and Internet sites that focused on holistic medicine. Slightly over half of the women went to the Internet to increase their knowledge base, link with other women, and enhance their ability to participate successfully in a biomedical setting. Hoffman-Goertz's and Clarke's (2000) recommend a degree of caution

concerning breast cancer sites because they vary with respect to information that would allow the user to assess the credibility of the information.

Personal contact with other people who could empathize provided another source of support for the women as they went through the process of justifying their decision. They expressed a great need to speak to other women who had been through the breast cancer experience. This contact helped to "stop the spinning" and relieve the worry of regretting the decision in the future. Organized support groups, such as Reach to Recovery (Canadian Cancer Society, 2001), provided positive examples that breast cancer is not the "end of the world", but perpetuated the negative mentality concerning survival of the "war on cancer". Reach to Recovery provided formal information meetings that were monitored to minimize medical advice or opinions. However, five of the women considered the informal sharing at these meetings to be intrusive and depressing at a time when the women were vulnerable. Volunteer groups face a delicate balancing act between providing emotional support to the women and guiding them to reputable information sources.

Research findings have revealed that formal support groups were particularly helpful for dealing with specific physiological symptoms, self-concept issues such as feelings of downward comparison and normalization, and development of interpersonal relationships skills (Samarel et al., 1998). The women in this study found that the formal groups that were organized by psychologists at the cancer institutes did not always provide a favorable atmosphere for sharing ideas about refusing adjuvant therapies. However, they

appreciated the sensitivity of the psychologist who facilitated the groups and affirmed the women's right to choose.

Healthcare Providers and Informed Consent

The "health care system" includes all health care providers that interact with women as biological and emotional beings (Masi, Mensah, & McLeod, 1995). Health care providers included both conventional medical professionals and alternative health care providers. Medical health care providers examine the biological factors that influenced the selection of treatment regimens for each patient (stage of disease, menopausal status, estrogen receptor status, age and comorbidities). Alternative therapists often used a combination of biological and mind/spirit interventions in order to return the women's bodies to a state of wellness (Jacobson, Workman, & Kronenberg, 1999).

Consultations with Health Care Providers

The oncologists and oncology nurses provided decisional support that included technical explanations of the therapeutic options, along with lists of possible outcomes that seemed to the women to involve a substantial amount of uncertainty. While the medical profession is ethically responsible for ensuring participation in this complex treatment decision making process (Dossetor & Cain, 1997), this information was not always forthcoming or comprehensible to the women in this study. Smith and McCarty (1992) suggested that a more fruitful approach for doctor-patient conversations is built on trust, support, understanding and care, as the patient tries "to make sense of what is happening and what possibilities for action offer what potential effects" (p. 825).

Women consulted with health care providers who they thought could offer them clarification: family doctors, surgeons, psychologists, oncologists who had lived through cancer themselves, plastic surgeons who would be performing the breast reconstruction, and alternative health care practitioners. They looked for individuals who they trusted, who shared their philosophies, and who demonstrated their commitment by investing time and showing concern. They appreciated being respected versus what several women described as "an assault on their belief system" by their primary oncologists. As in previous studies, these women perceived the second opinions to be more valid than the oncologists' recommendations (Siminoff & Fetting, 1991). This study demonstrated how positive rapport encouraged women to return to specific health care providers.

Conflicts with Health Care Providers

The women made a point of stating that they do not negate the expertise of the oncologists. They recognized that "Western medicine is not where it is for nothing", and they did not want to burn their bridges because they may need the oncologists in the future. Hewlett (1996) argued that patient's fear of upsetting the relationship with their physicians affects the patient's autonomy, and therefore their consent is not completely voluntary. The women in this study exhibited their autonomy by arriving at their appointments equipped with statistics concerning the risks and benefits in order to participate in an informed discussion about the prescribed therapies and their alternate choices, not to initiate conflict.

Jacobs (2000) defined risk as the probability of an adverse, unpleasant, or dangerous event occurring, or the potential realization of unwanted consequences

of an event. Each woman's perception and acceptance of risk depended on her perception of what was "safe enough". The women perceived that their oncologists felt uncomfortable and challenged by their conviction to refuse risky therapies. Thirteen women experienced conflict concerning their decisions and were actually told by the oncologists that their decisions were not the correct answers. Richards et al. (1995) reminded physicians that patients' preferences for being involved in decision making is likely to increase, and that clearly they should be enabled to do so without experiencing negative repercussions.

The women did not appreciate being dismissed when they did not accept adjuvant therapies. Five women said that they never got the results from their diagnostic tests because they were told it was "of no consequence if they were not accepting the adjuvant therapies". They thought that if they took the time to go through the tests, they had the right to be informed of the results. Sherwin (1998) reminds us that the model of informed consent is built on the assumption that patients are articulate, intelligent, and accustomed to making decisions about the course of their lives. Therefore, it is not fair to the women to limit their knowledge because the physicians feel that the test results were of no consequence to them once they refuse the recommended therapies.

The women who had utilized alternative health care providers prior to their diagnosis of breast cancer continued to use alternative therapies either exclusively or in conjunction with adjuvant therapies. Studies confirm that more than half of today's CAM practitioners are medical practitioners, generalists, and psychiatrists (Cassileth & Chapman, 1996). Several oncologists thought that using

alternative medicine exclusively was equivalent to doing nothing. The women who preferred alternative medicine thought that working on the whole body was more effective and comprehensive than invasive adjuvant therapies. Lynoe (1992) suggested that "If the patient insists on receiving an alternative medical treatment, towards which the physician (and the profession) adopts a negative attitude, the physician can thereby drive the patient into the arms of the practitioner of alternative medicine" (p. 220). He also argues that conflicts that arise as a result of a patient's request to substitute alternative medical care and a physician's resistance to their decision, may require a compromise between the two parties.

Traditional medical ethics are imbedded in a branch of Western philosophy (Barkes, 1979). While the basic premise is that every human being has the right to determine what shall be done to her/his own body, it is often left to the discretion of the physician to determine what she/he should be told to allow her/him to make a rational decision (Sherwin, 1998). The women who used alternative therapies either exclusively, or in conjunction with adjuvant therapies, perceived the need for greater acceptance of the alternative therapies by western medical professionals. They recognized the need for proper scientific evidence and they did not endorse an open system that allowed every "snake oil cure" to be subsidized. While the cultural norm for western medical practitioners is not usually to embrace alternative medicine, the women still hope that their values and beliefs will be respected.

Socio-political Environment

Work relates to both the socio-economic and physical environments where the women reside, and impacts the health of the individual and her family (Badir, 1993). The work role and the social relations at work influence both physical and mental health. The majority of women in this study perceived stress to be the major cause of cancer, and ten women mentioned work stress in particular.

Eleven women had to terminate their work and four women postponed their graduate school studies when they were diagnosed with breast cancer. Several women in this study had to rely on their insurance to supplement their families' income during their recovery from breast cancer surgery and adjuvant therapies. This was not always considered a hardship if the women preferred to leave their stressful work environments. Hilton (1996) found that women's ability to return to normal was severely constrained by the side effects of breast cancer and adjuvant therapies, such as fatigue and altered body image. One woman sold her company and two women had to give up their careers because their arms were compromised by the removal of the lymph nodes.

Ellers (1993) study reported on the financial burden of paying for medical care for patients who are no longer contributing to the family income. Three husbands put their career changes on hold to ensure the continuation of medical benefits. Two women talked about their husband's resentment concerning the need to hire housekeepers. These women wanted to return to "normal" to reduce the financial burden they felt that they were placing on their families. Removing the women from the workforce impacts their families, their employers, the

insurance companies, the health care systems, and the socio-political welfare of their communities (Bubolz & Sontag, 1993).

The broader health care system exists within a socio-political environment. This affects whether there are medical facilities or current therapies available to the women and the extent to which alternative therapies are recognized and supported (Sherwin, 1998). One woman was told she would have to go to the United States to have her radiation therapy, at her expense. When she refused to leave her family and support system, the cancer institute made arrangements for her to go to a city in the same province, and she was still responsible for accommodation and travel. Socio-economic factors had an enormous impact on the women's decisions and continuing effort should be made to reduce the financial burden that accompanies breast cancer. Further research should investigate the true costs of accepting prescribed therapies.

Observations and Conclusions

The challenge of studying women who refused adjuvant therapies was twofold: 1) there was a lack of research in the area of refusing breast cancer therapies; and 2) there were great diversities in the choices presented to these women. The researcher's decision to use grounded theory, within a human ecological framework, is summed up in an explanation by Crooks (2001):

> Grounded theory research reveals the world view of women by seeking to understand the social construction of meaning and action by asking questions about point of view, influences on action, problem-solving

> strategies, definition of action and situation, effect of past experiences, and, finally, future plans. (p. 25)

It was clear that there was a complex social construction of meaning and action that shaped the women's preferences for biomedical or alternative medicine. The preferences in this particular group of women ranged from modified use of biomedical interventions to complete use of alternative medicine after the acceptance of surgery for the removal of the tumor. Excluded from this study were women who accepted all prescribed therapies and women who refused all biomedical therapies, including surgery.

Before the diagnosis of breast cancer, the women were established on a point along the preference continuum from prescribed to alternative therapies. Therefore, when they were given the initial diagnosis of breast cancer, they began to justify their therapeutic decisions in accordance with their position along that line of preference. The concept of passing the decision-making process through a pre-established preference filter has not been described in the literature prior to this study. The women who preferred alternative therapies were not deterred from consulting with oncologists because they wanted to be completely informed, in case the oncologists had therapies that were compatible with the women's perspectives on health and wellness.

The literature that the women in this study referred to ranged from popular magazines, to biomedical books and journals, to alternative books and articles. Well meaning family and friends continually provided information that they believed was valuable. There was a point for all the women when they became

overloaded with information. Inevitably it was each woman's responsibility to decide what she believed was the truth, because she was the only one who had to live or die with the decision.

The women became disillusioned when they realized that there were no definitive answers to their questions concerning the breast cancer. There does not appear to be a "best method" for ensuring the eradication of the cancer cells. Second medical opinions were solicited from doctors, surgeons, medical specialists and alternative practitioners. It became a balancing act when the woman and the various health care providers were not in agreement. However, when rapport was established with the health provider who provided the second opinion, the women invariably placed their trust in the second opinion, a phenomenon that has been observed in previous studies.

The women looked for support from people who could empathize with their breast cancer experiences. Relationships with family, friends, and co-workers were often difficult because they were afraid of the woman's potential pain and death and unsure of what to say. There was a camaraderie that was described by all of the women who cherished the opportunity to share their stories with another woman who had lived through the experience of breast cancer. The women did caution others to ensure that the person they talk to has similar preferences concerning traditional and/or alternative therapies.

When the women who preferred traditional medical interventions discovered risks that were unacceptable, they presented an argument for modifying the treatment regimens. The women who preferred an alternative

approach began their healing either by boosting their immune system or turning to prayer and discernment. Conflict would arise when a woman's physicians, husband or children were not observing the decisions from the same points along the preference line. Physicians' reactions ranged from anger and defensiveness, to continual reintroduction of the therapies, to acceptance of the women's preferences. Frequently husbands were convinced to support their wives, or the wives were convinced to accept therapies that they preferred to refuse. The women who were persuaded by their children to accept a portion of the prescribed therapies, continued to question their acceptance of those therapies.

There were economic considerations that resulted from being unable to work or maintain the household. Often husbands were upset when they had to pay for a housekeeper to clean the house. Several husbands had to place their career changes on hold because their wives needed the medical benefits that accompanied their existing position. The women also had to terminate work during chemotherapy or radiation treatments, or they made the decision to quit because they linked the stress from their work with their bodies inability to fight off cancer cells. Economic hardships that result from debilitating cancer therapies must be studied further to determine ways to reduce the burdens that the women and their families face.

This small group of women lived with a disease that was caused by factors that affected their bodies, minds, and spirits. At the end of the decision making process, the women had gained knowledge and wisdom. They made their

decisions based on their unique positions in this world, and their choices touched and shaped everyone within their intricate ecological system.

Limitations and Delimitations of the Study

There are several factors that may decrease the validity and reliability of this study and therefore may be seen as limitations. The delimitations are potential restrictions related to the range of participant selection.

The object of grounded theory is to generate theory that is occurring in a specific context, thereby eliciting meaning in a particular situation (Morse & Field, 1995). This study was conducted on a small theoretical sample that might have allowed for only limited variability. Therefore, the decision making process that the participants described may not be representative of all women who refused prescribed adjuvant breast cancer therapies. Perhaps those women motivated to participate felt most comfortable with their decision or had a special desire to share those decisions.

The internal validity, or the degree to which the findings represent the reality of the situation, can be threatened by two sources of subjectivity: the "researcher-as-instrument" and the quality of the respondents' reports (Field & Morse, 1985). Since the researcher had experienced breast cancer, internal validity may have been affected by the unconscious expectations that were communicated to the respondents. Data were collected through the use of broad, open-ended questions and neutral probe questions that allowed respondents to set the direction of their accounts. Validity may also be decreased by the

respondents' inability to accurately recall perceptions of events and responses to those events (Montgomery, Lydon, & Lloyd, 1999).

The first delimitation is that the participants were within a similar socioeconomic level, even though they were purposely selected from a fairly wide area. Fourteen of the seventeen women had post-secondary education. Second, the study was limited to English speaking Canadian women from 35 to 70 years of age. Third, the women who refused all traditional medical therapies, including surgery, were not included in this study because the stage of their breast cancer could not be determined. Women with co-morbidities were not selected because their physicians were uncertain of the value of adjuvant therapies.

Recommendations for Women

The women in this study provided the following advice to anyone who is diagnosed with breast cancer. Women must take the time required to absorb the fact that they have been given a life-threatening diagnosis. They need to gather information to clarify areas where they are not conversant, and when appropriate, share their findings with their families, counselors/psychologists, and other health care providers. They highly recommended contacting other women who have been through this same decision making process. Women need tutors to help them decipher the new language and acknowledge the emotional challenge of breast cancer.

The realization that there were no guarantees that the preferred treatments would be successful was devastating and caused women to feel lost and out of control. They were afraid that the cancer would metastasize within weeks, and

that the oncologist would be angry if they appeared indecisive and ignorant. The women were very creative in their attempts to regain control. One woman tattooed a string of tiny flowers across the scar on her chest. Another woman joined a Dragon Boat racing team. One mother drove from Alberta to Alaska with her daughter. The list was as varied as the number of women that were interviewed.

Information concerning either prescribed therapies or alternative medicine has the potential to be biased. It was not easy for women to determine what research was reputable. Frustration would arise when new information would contradict previous findings. The women emphasized the need to go to the original source of information, and to recognize who would benefit most from the therapies, the woman or the product manufacturer. The women stated that they do not want to regret their choices because they were uninformed. Accessibility of information does not only refer to the physical ability to get the research. The facts need to be in a language that is clear and free from indecipherable medical terminology.

When the women in this study explained the intricate details of their decision making process, they were always quick to state "it was my individual situation" and "every woman needs to manage her own life". There are no promises, and these women felt that they were responsible for deciding their personal priorities. They believe that when you let someone else control the decision making process it creates conflict within yourself, especially when the results are negative. They already carry with them guilt for having breast cancer.

This was evident in the lifestyle changes that the women made: drastically changing their diets; detoxifying their body; introducing exercise or relaxation practices; and leaving painful relationships and draining work situations.

There are more lessons to learn than the statistical probabilities of each prescribed or alternative therapy. Women must identify and sort through the emotions they are experiencing. They need to determine if they are justified in their concerns and sort out whether they are on the right paths. Finally women should take their time, complete the process of information gathering, and then listen to the body, mind, and spirit, and trust that they have the inner wisdom and fortitude to choose the right course of action.

Implications for Health Care Providers

It takes time to look for all the resources available to women who have breast cancer. The first resource will often be the specialists who have reviewed the specific case and prepared the course of therapies. While physicians, in particular specialists, have a limited amount of time available to provide information, they cannot expect the women to comprehend all of the ramifications that may arise in the next six to eight months of therapeutic interventions. It takes time to truly comprehend the extent of the prescribed therapies and review the alternatives. Currently, the time line is fairly rigid for accepting the specialists' recommendations, and the women are asking for more time and less pressure in thinking through their decisions, and weighing through the options that will affect them as long as they live.

The women asked that their physicians respect and validate their extensive search for knowledge. They know that something must be done and they want to be allowed to express what they know from their valid perspective. While statistics are important, women know that they have already become the "one in nine women" who statistically will get breast cancer. They have more to consider than merely "what the literature bears out": they are mothers, wives, daughters, sisters, employees, and so on. Each woman has to be responsible for her decisions and health care providers must be able to let her make her choice, even if statistically it seems incorrect. The patient communication strategies employed by health care professionals should be evaluated and reviewed frequently.

Oncology nurses are available to field questions for women at the cancer institutes and triage nurses can be contacted by phone. However, the women in this study commented on the limitations of any health care provider who has not lived through the fears associated with cancer. Collaboration between the cancer institutions and Reach to Recovery or similar mentoring programs already exists. The women suggested creating a salaried mentoring position, occupied by a woman who has been through breast cancer, not a volunteer position that has mandated limitations concerning what can be discussed. Current information in the form of pamphlets, books, videos and lists of appropriate web sites must continue to be available.

There were different points of view expressed by the women in this study concerning the provision of information. Several physicians supplied their patients with Dr. Susan Love's Breast book, and one surgeon walked with the

woman down to the patient library. In contrast, other women felt that they had to search alone for any additional information. They viewed the cancer clinic as a site for clinical action, not a place to find information. While one oncologist's persistence appeared to demonstrate a passion for her perspective, another doctor's perseverance was perceived to be disrespectful. These conflicting stories emphasize the importance of establishing a relationship between the healthcare provider and the patient that will facilitate the decision making process. Health care providers need to be able to interpret the woman's desire for information and be an advocate for the patient as she moves through the healthcare system. Further research that examines learning needs of patients may shed some light on this dilemma. Part of the answer may lie in the statement that one woman made concerning the unsolicited second explanation that was given by the head of oncology after the first oncologist became defensive: "His information was not different, it was presented differently! He knew I had taken it all in, and got a different perspective."

There were several women in this study who had lost a close relative to cancer. They admitted that their initial response to prescribed therapies was fear. These women remembered the pain and recounted details of their loved one's surgeries and therapies, the reaction of their family members, and the social isolation that surrounded the loved one and the woman after the death. Listening to the woman's fears and past experiences would allow the health care provider to determine what the patient wants to hear, or what she is willing to hear. Without the knowledge of the patient's past medical experiences, it is impossible to predict

their needs in the current situation. This may explain why women went to health care providers with whom they had established trust and rapport and who had an understanding of their medical experiences, not just their medical history.

The women had great admiration and appreciation for psychologists at the cancer institutes who took the time to listen to the individual concerns, fears and considerations concerning the women's commitments to their families and communities. Psychologists also facilitated small group discussions for women who had breast cancer. Cancer institutes should be applauded for providing these services of compassion and support for the patients, their spouses, and their families. The psychologists could also be an excellent resource for teaching other health care professionals the art of listening.

Several of the women in this study matched the patients in Adler's study who used complementary and alternative medicine (CAM) before they were diagnosed with cancer: these patients "challenge the stereotype of the 'desperate' patient who is willing to try anything after receiving such a diagnosis" (p. 219). The women did extensive research into the therapies that were prescribed and alternative therapies that were recommended or that they discovered through reading, searching the Internet, personal contacts, or the media. Half of the women in this study consulted alternative therapists after their surgery. Previous positive experiences with CAM strengthened the women's resolve to continue seeking information from alternative therapists. They stated that the alternative care facilities provided them with continual support and information, which the women appreciated.

However, the women commented that these facilities could have connected them with other like minded breast cancer survivors, because they did not meet many women at other popular support groups who accepted alternative therapies. Women need role models of other women who share their philosophical perspectives on health and wellness. Cancer patients are making personal decisions to blend biomedical science and alternative approaches to cancer therapy, and they hope that their informal decisions will be a catalyst for formal collaborations between the two methodologies.

Recommendations for Further Research

This study raises a number of issues that may guide further research in the area of decision making processes. Since the purpose of an exploratory study is to generate hypotheses about a specific situation that later research can refine, expand, and test, hypotheses are included following each recommendation.

1. An important finding of this research was the polarization of decisions along a pre-established preference line that ranged from biomedical to alternative medicine. Expanding the investigation to include men and women who are making decisions concerning therapies for other life threatening diseases could serve to validate, clarify and possibly expand the findings of this research. A comparison of patients who prefer the biomedical approach and those who prefer alternative medicine would illuminate the differences in their decision making strategies.

   Hypothesis: Patients will choose therapies that are congruent with their pre-established preferences for biomedical or alternative medicine.

Patients' current information seeking practices involve a network of support that was established prior to the diagnosis of the disease.

2. Although the focus of this study was limited to the women's descriptions of the decision making process, their responses influenced and were influenced by their perceptions and interactions with health care providers, family members, friends, and other people in their community. The knowledge gained about women's justification of their refusals would be more complete if it were compared with the reactions of health care providers, husbands, children, and others.

   Hypothesis:

   When health care providers or significant family members have a preference for biomedical or alternative medicine that differs from the women's preferences, conflict will arise. Conflict will continue for the party that does not control the final decision, unless they are persuaded to accept the other party's decisions.

3. The women went to numerous different sources to gather information before they made their decisions: libraries, bookstores, the Internet, health food stores, health care providers, Reach to Recovery, and so on. Investigation of the sources of information would reveal whether the information from these various sources is accurate, adequate, accessible, and understandable.

   Hypothesis: Patients are able to access enough reliable information to allow them to make an accurate decision concerning the risks and benefits of the

prescribed therapies. They refuse therapies because they are convinced that the risks are too great in comparison with the benefits.

4. There were women who were not eligible for this study because they did not have surgery to determine the staging of their breast cancer, and subsequent prescription of adjuvant therapies. Further research could investigate women who have refused surgery as well as all breast cancer therapies, to determine the factors that lead them to their decisions.

   Hypothesis: Women that find a breast lump and refuse all biomedical interventions do so because they perceive a decrease in their quality of life for the following reasons: 1) they have comorbidities; 2) they are over 70; and/or 3) they prefer to rely on alternative therapies or healing practices.

5. Communication between patients and healthcare providers is often inequitable because of the power differential that exists. Information sessions often follow the physical examination and continue in the examination room while the woman is still in the clinic gown. The healthcare provider is standing and the woman is sitting. Provisions should be made for the information exchange to occur in an environment that encourages an exchange of information concerning the prescribed therapies and the impact that those therapies will have on the patient from her personal perspective as well as the healthcare provider's medical perspective.

   Hypothesis: Providing an environment that is conducive to sharing information will encourage both the healthcare provider and the patient to share their impressions concerning the impact of the prescribed therapies on

the woman's life. Communication will be enhanced and future tensions will be allayed.

6. The women in this study who embraced alternative medicine explained that the doctors at the holistic clinics encouraged them to look at all the options. They were willing to help relieve side effects if the woman preferred traditional therapies, and they had literature on all the therapies that could be prescribed. It would be advantageous if the healthcare provider had access to information about CAM so that they could have an informed discussion with their patients that are as thorough as the CAM practitioners are reputed to be.

   Hypothesis: Patients may perceive that the CAM practitioners are providing a more comprehensive explanation of all the therapeutic alternatives.

   Expanding the knowledge base of biomedical practitioners to include information about the risks and benefits of CAM will allow them to partake in a broader discussion with patients who wish to discuss the risks and benefits associated with traditional medicine and CAM.

7. The women in this study expressed the need for an adequate amount of time to make an informed decision. They felt pressured to make an immediate choice concerning the prescribed treatments. They wanted to know if the scheduling of therapies was confounded by arbitrary requirements within the health care systems or represented a true reflection of the urgency of their situation.

   Hypotheses: Time frames are more reflexive of the availability of services than of the urgency of the recommended therapies.

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APPENDIX A1: PARTICIPANT'S INFORMATION SHEET

PARTICIPATION IN RESEARCH PROGRAMS IS ENTIRELY VOLUNTARY. PATIENTS AND VOLUNTEERS ARE ASSURED THAT THEY MAY DECLINE TO PARTICIPATE OR TO WITHDRAW FROM THE STUDY AT ANY TIME WITHOUT PREJUDICE.

Title: Refusal of Chemotherapy or Radiation Treatments

Conducted by: Louanne Keenan
Doctoral Student, Department of Human Ecology, University of Alberta
Faculty of Agriculture, Forestry, and Home Economics
Edmonton, Alberta
(Telephone: 780-467-6471)

Thesis Advisor: Dr. Nancy Gibson
Chair of Human Ecology
Faculty of Agriculture, Forestry, and Home Economics
University of Alberta
Edmonton, Alberta
(Telephone: 780-492-3883)

I am Louanne Keenan, a graduate student at the University of Alberta. I would like to talk to women who have breast cancer and who decided not to have any treatments after their surgery. I would also like to talk to women who have decided to stop their treatments early. I think that talking to women will help other women who have to make huge decisions.

There are no health risks in this study. However, if the questions I ask make you feel uncomfortable, I can offer an appropriate person to talk to you.

If you would like to be in the study, I will make one 1-2 hour interview with you at your house, and possibly one or two short interviews for clarification of the first interviews. The interview can also be somewhere else, if that is what you prefer. I will do these interviews. The interviews will be tape-recorded. You can ask me to turn off the tape recorder anytime. Then I will type them onto a computer disk. You will not have to spend any extra time in the hospital. This interview is not part of your regular care.

The tapes of your interviews will be stored in a locked file. They will each have a special identification number only. This same number will be placed on the computer disk with your interviews. The list that has your name and your identification number will be stored in a locked file. The computer disks containing the interviews will also be stored in locked files. My thesis advisor and I are the only persons who will be able to look at these materials.

The tapes and transcripts will only be used for research and educational purposes, and your name will never be mentioned. Sometimes your words will be used so that your ideas will be clear. When I am interviewing you, you can tell me to turn off the tape recorder at any time. During this time, if you agree, I will take notes.

If you have any questions about the study, or need to drop out at any time, please contact me, Louanne Keenan at the 780-467-6471. You can also leave a message at the university (780-492-8338).

_____ _____

Participant's initials Date

(The readability level of this letter grade 6.8.)

APPENDIX A2: PARTICIPANT'S CONSENT FORM

REFUSAL OF CHEMOTHERAPY OR RADIATION TREATMENT

CONSENT FOR PARTICIPANTS

I accept that the information about the study was explained to me. Any questions I have asked about the study have been answered to my liking. I have been informed of my options to participation in this study. I know about the possible risks and discomforts. I understand that I can call Louanne Keenan, at 467-6471. She will answer my questions about the study.

If I decide to stop being in the study at any time, I may do so without influence to my care.

I understand that I will receive a copy of the information sheet and this consent form. I understand that information resulting from this study may be reported. I understand that my name will never be used and I will not be identified.

_____ _____

(Name of Participant) (Signature of Participant)

_____ _____

(Name of Witness) (Signature of Witness)

_____ _____

(Name of Investigator) (Signature of Investigator)

_____

(Date)

(The readability level of this letter grade 7.6.)

APPENDIX B: INTERVIEW SCHEDULE

FIRST INTERVIEW

Questions were asked using the participant's own language in order to relate to them on their own terms. As Denzin (1989) puts it, "the phrasing of the questions and the order in which they are asked are altered to fit each individual. Open-ended interviewing assumes that meanings, understandings, and interpretations cannot be standardized" (p. 42) (Denzin, 1989). While questions are not prescribed beforehand, the general topics and themes of the interview are typically already decided upon (Rice & Ezzy, 1999). Understanding is best gained through "questions born of a genuine curiosity for that which is 'not-known' about that which has just been said" (Anderson H. & Goolishian HA. 1988). Questions such as "What was that like for you?" or "Tell me about that" were used to elicit the participant's experience in her own words.

The Open-ended Interview

1. The event of breast cancer: How was the lump in your breast discovered?
   - Tell me about the events and circumstances surrounding your diagnosis and surgery.
   - If you choose any prescribed therapies, did you experience any side effects?
2. Information Sources
   - Where did you get your information concerning breast cancer and therapies?
   - What do you know about the risks and benefits of the prescribed therapies?
   - Do you have any previous experiences with cancer in your family?
3. Decision
   - Describe the prescribed therapies that you accepted and/or refused?
   - Describe any alternative therapies that you used?
   - How did you personally feel after your decision?
4. Health care providers
   - Describe your relationships with your health care providers
   - Describe the health care providers reaction to your decision.
5. Ramifications of the Decision
   - What were the reactions of your family members to your decision?
   - What were the reactions of friends to your decision?
6. What advice would you want to share with other women and health care providers?

APPENDIX C: CONVENTIONAL BREAST CANCER THERAPIES

Mastectomy

Mastectomy is the surgery of choice for women who have had multiple cancers in the breast, a large cancer-to-breast ratio, contraindications to radiation therapy, or a diffuse cancer where the surgeon is unable to achieve a margin of normal tissue around the removed cancer (Schwartz et al., 2000). Obtaining clear margins is crucial because it is clear that most local recurrence rates represent residual local disease that has not been adequately excised. In addition, radiation therapy has not been able to treat residual disease in the breast adequately (Veno-Sharp & Mrozek-Orlowski, 1998).

Total mastectomy refers to removal of the breast, including the tail of Spence, which extends into the axillary space (the hair-bearing hollow below the shoulder) (Roses, 1999). It is within the hollow of the axilla that lymph nodes are palpated clinically and surgically removed. A modified radical mastectomy involves the same surgery as a total mastectomy, with the addition of more extensive axillary lymph node dissection to determine metastases to the lymph nodes, but preserves the pectoralis major muscle (Singletary & Robb, 2000).

Breast Conservation with Lumpectomy and Radiation Therapy

Since the introduction of screening mammography and increased awareness in women, the majority of breast carcinoma patients are diagnosed earlier (i.e., in clinical Stage I) (Schwartz et al., 2000). By 1995, 45.8% of breast carcinoma patients were diagnosed early as Stage 0 or I, and 58% of these cases were treated with a lumpectomy (Bland et al., 1998). A lumpectomy alone

involves the surgical excision of the tumor with clear margins of at least 10 mm to reduce the likelihood of local recurrence without removing an excessive amount of tissue (Schwartz et al., 2000). Radiation therapy eradicates microscopic residual disease (Dow, 1996). The NSABP B-06 trial determined that the risk of local recurrence after local excision alone was as high as 35%, compared to 10% when combined with radiotherapy (Schwartz et al., 2000). A lumpectomy with postoperative radiation would include the removal of the tumor, usually with lymph nodes sampling, followed by radiation therapy for 3-6 weeks to the entire breast (Rosenthal, 1999).

Axillary Node Dissection

Axillary node dissection (ALND) is performed in patients with breast carcinoma mainly for staging purposes and to determine the need for adjuvant treatment (Schrenk, Rieger, Shamiyeh, & Wayand, 2000). Numerous factors aid in the prediction of cancer metastases: the size and characteristics of the tumor, the number of axillary lymph nodes that contain cancer, the appearance of the tumor cells (rate of cell division and genetic code), the number of genes, and whether there are mutations in the genes that control cell growth (Monson & Harwood, 1998). The prognosis is more favorable when the breast tumor is smaller, demonstrates less aggressive behavior, has a lower malignancy grade and a lower number of pathologically involved lymph nodes. (Hoebers et al., 2000). However, Roses (1999) stated that the therapeutic value of axillary dissection in the absence of palpable lymphadenopathy is controversial, and it should only be applied when the pathologic findings would alter adjuvant therapeutic strategies.

Since the rate of axillary node metastases in patients with small tumors is relatively low, alternative axillary treatment strategies for early stage breast carcinoma include axillary radiotherapy (ART), no axillary therapy in case of very favorable prognostic criteria, and sentinel lymph node biopsy (Hoebers et al., 2000).

The routine performance of axillary dissection for patients with breast carcinoma has been questioned due to the relatively high postoperative morbidity rate resulting from the procedure (Schrenk et al., 2000). Although surgeons have traditionally felt this morbidity to be of substantial effect, quality of life studies from the patient's perspective indicate that 40-60% of patients experiences long-term side effects (Singletary, 1998). The potential negative long-term effects of axillary node dissection include lymphedema of the arm, sensory numbness, pain, limitation of motion and strength of the arm and/or shoulder, and decreased sweat production (Hack, Cohen, Katz, Robson, & Gass, 1999; Singletary & Robb, 2000). Once women develop lymphedema, few treatment options are available, and women suffer continuous pain (Wooddell & Hess, 1998). Several women with breast cancer who were interviewed by Wooddell and Hess (1998) considered it "insanity" to mutilate a woman and introduce the handicap of a compromised arm to determine if chemotherapy is necessary when, in fact, chemotherapy is being prescribed regardless of lymph node status.

A new sentinel lymph node (SLN) biopsy technique has been shown to stage the axilla accurately and spares the patient the morbidity resulting from axillary dissection (Schrenk et al., 2000). This procedure entails injecting

radioactive dye near the primary tumor, allowing the first node in the lymph drainage to be identified (Singletary & Robb, 2000). The SLN biopsy electively removes the first lymph node that gets the drainage from the breast carcinoma, therefore providing the pathologist with the lymph node that carries the highest probability of containing potential metastases (Schrenk et al., 2000). If negative, axillary dissection can be avoided. Due to the limited dissection, it may be suggested that SLN biopsy is associated with nearly zero morbidity, because one lymph node or a few lymph nodes are identified in the axilla and are excised electively without major dissection (Jackson et al., 2000). Recent studies of sentinel lymph node biopsy have yielded 80-100% detection rates and 0-17% false-negative rates (Krag et al., 1998; Veronesi et al., 1997).

Cytotoxic Chemotherapy

The National Cancer Institute (1986) advocated for the standard use of chemotherapy for premenopausal node-positive patients and a change in the perception of the disease itself from one that was sometimes localized to one that was always systemic (Levitt & Kennedy, 1998). Still questioned, however, is whether women with negative nodes and lesions of 1 cm or less benefit from adjuvant chemotherapy (Schwartz et al., 2000). Currently, the most effective drug combination to treat premenopausal women with breast cancer are 5-fluorouracil, methotrexate, cyclophoshamide or doxorubicin (CMF or CAF).

New approaches to drug therapy of breast cancer involve strategies to increase dose intensity, which include dose escalations, dose density scheduling, and the use of cytokines (G-CSF). Other new modalities may include inhibitors of

cancer cell proliferation, exploitation of growth factor receptors, monoclonal antibodies, immunology, and vaccines (Levitt & Kennedy, 1998).

Side Effects of Cytotoxic Chemotherapy

Chemotherapy usually involves intravenous treatments every few weeks over several months. Acute side effects may include nausea/vomiting, alopecia, mucositis, neutropenia, thrombocytopenia, and fatigue. An especially troubling long-term side effect is premature menopause, which may result in vaginal dryness, changes in sexual desire, weight gain, and an increased risk of cardiovascular disease and osteoporosis (Goodwin et al., 1999; Singletary & Robb, 2000). Decreased cognitive function in patients after completion of their adjuvant chemotherapy was observed in several studies (Winchester, 2000). Attention, speed of information process, motor speed, and visual memory seemed to be the most frequently impaired functions (Schagen et al., 1999). High-dose regimens used in combination with bone marrow or stem cell transplant may result in organ toxicity with resultant fatigue, shortness of breath, or other side effects (Monson & Harwood, 1998).

Endocrine Therapy

Hormonal suppression was the first systemic approach used as an adjuvant to mastectomy for the treatment of metastatic disease. Early studies of the effects of hormonal suppression by surgery (ovarioectomy) indicated a benefit to patients with advanced primary, recurrent, or distant metastatic disease (Levitt & Kennedy, 1998). Irradiation also was shown to elicit an artificial menopause in inoperable breast cancer. Because of the success of ovarian ablation on metastatic

disease, its use as a preventative treatment against disease recurrence was considered. In 1934, ovarian oblation was introduced as routine therapy along with radical mastectomy to inhibit metastatic disease (Levitt & Kennedy, 1998). The term 'prophylactic' artificial menopause was coined, and by 1957, prophylactic ovariectomy was considered to delay the onset of recurrence and to prolong life. However, based on a study that showed no survival difference between prophylactic ovariectomy and ovarian oblation at the time of recurrence, there followed a marked cessation of the use of prophylactic ovariectomy for many years (Levitt & Kennedy, 1998). However, ovarian ablation (referred to as 'castration' by Rutqvist, 1998) is associated with several adverse side effects such as hot flashes, vaginal dryness, bone demineralization, and possibly an increased risk of cardiovascular disease (Rutqvist, 1998).

The estrogen antagonist, tamoxifen, was introduced as an effective anti-breast agent over 20 years ago and has evolved as one of the current treatment options for subgroups of breast cancer patients. Initial reports showed that tumors containing estrogen receptors and those that responded to previous hormonal manipulation were most likely to respond to tamoxifen in a range of 60-70%. Other benefits include low cost and easy administration (Levitt & Kennedy, 1998). In a 1995 consensus panel, tamoxifen was regarded as the adjuvant treatment of choice for all estrogen receptor-positive, node-positive, postmenopausal patients and all elderly patients. Tamoxifen is now used in postmenopausal patients where the lesions are greater than 1 cm (stage 1) (Levitt & Kennedy, 1998).

Side Effects of Endocrine Therapy

Hormone therapies, such as tamoxifen, an antiestrogen, are used more commonly in postmenopausal women and for those women whose tumors are estrogen receptor positive. The current recommendation is for women to take this medication daily for five years. There are generally fewer side effects with tamoxifen, but they may be troubling due to the duration of treatment. The most common are nausea, vomiting, rash, hot flashes, lightheadedness, vaginal discharge, weight gain, and headaches (Monson & Harwood, 1998). However, Rutqvist (1998) reported tamoxifen-associated increases in thrombembolic events (obstruction by clot of blood) and an increased incidence of endometrial cancer. Tamoxifen has been referred to as a "disease substitution" because it increases the risk of endometrial cancer (Wooddell & Hess, 1998). Alternative endocrine agents without genotoxic agents potential are theoretically more attractive.

A review of the current information on hormone replacement therapy in patients with diagnosed breast cancer by Chlebowski and McTiernan (1999) considers tamoxifen-related outcomes an acceptable risk: "Among 50-year-old postmenopausal women with node-positive, receptor-positive disease, approximately 500 of 1,000 patients observed for 10 years will die of breast cancer. Tamoxifen will reduce this risk by approximately 25% and result in 125 fewer breast cancer deaths. Against this substantial benefit, the excess mortality associated with endometrial carcinoma of about one per 1,000 patients treated with tamoxifen becomes an acceptable risk" (Chlebowski & McTiernan, 1999, p. 136).

Radiation Therapy

Primary axillary radiotherapy for postmenopausal women with clinically lymph node negative, early stage carcinoma was found to result in low axillary lymph node recurrence rates with only limited late complications. Therefore, primary axillary radiotherapy should be considered as axillary treatment in selected patients as an alternative to axillary lymph node dissection.

Node-positive patients treated with adjuvant postoperative megavoltage irradiation, which included the internal mammary chain, had a significant 37% relative reduction of distant metastases ($p = 0.01$) and a 22% relative reduction of deaths of borderline significance ($p = 0.06$) versus the non-irradiation patients. For early disease (stages I and II), nodal irradiation is used as needed, primarily in women with positive nodes and or lesions between 2 and 5 cm (Levitt & Kennedy, 1998). For locally advanced disease (stage III), chest wall irradiation is added to nodal irradiation (Levitt & Kennedy, 1998).

Breast Reconstruction

In addition to decisions about surgery and systemic treatment, women who choose mastectomy (or for whom lumpectomy is not an option) may also opt for reconstructive surgery. There are two methods of breast reconstruction that are used most frequently. The first involves insertion of a tissue expander under the chest wall muscle, several weeks of gradual expansion of the skin by injection of saline into the expander, then replacement of the expander with a silicone shell breast implant filled with either silicone gel or saline (Monson & Harwood, 1998). The second technique involves the creation of a breast mound from the

skin and fat located in one of three different areas: the lower abdomen, called a TRAM (transversus abdominus myocutaneous) flap; the triangular muscle that originates from the spines of the lumbar and sacral vertebrae on the back, called a LD (latissimus dorsi) flap; and the free flap reconstruction that involves detaching tissue from the gluteus maximus (buttock) area or the lateral thighs (Winchester, 2000). The viability of the TRAM flap and the LD flap are considered most effective because the tissue is maintained through its attachment to the trans rectus abdominus muscle (Fraker & Edwards, 1998; Monson & Harwood, 1998).

Future Directions

As more is discovered about the signal pathways and receptors involved in the growth regulation of tumor cells, it will be possible to design antibodies capable of inhibiting tumor growth and augmenting the effects of chemotherapy (Levitt & Kennedy, 1998). Paclitaxel is from a class of drugs, the taxanes, that have antimicrotubule activity (Maiche, Jekunen, Kaleva-Kerola, & Sequeiros, 2000). Gene therapy may allow the human multi-drug resistance (MDR) gene to be transfected into human marrow progenitors to instill a preferential resistance to a chemotherapy drug such as paclitaxel (Levitt & Kennedy, 1998). Recent scientific advances in the understanding of immunology have led to a renewed interest in immunotherapy. The use of systemically administered cytokines to enhance the immune response, together with the identification of tumor-associated antigens have the potential to produce specific cancer immunotherapies (Plunkett & Miles, 1998). Cancer vaccines have also been developed. These tumor -associated antigens can now be presented in a variety of ways to the

immune system in an effort to enhance their immunogenicity and promote tumorolysis (Plunkett & Miles, 1998). Other therapeutic possibilities include inhibitors of angiogenesis and matrix metalloproteinases, and retinoid-induced differentiation, (Singletary, 1998).

APPENDIX D: POSTER FOR VOLUNTEERS

VOLUNTEERS NEEDED

I am a graduate student at the University of Alberta doing a study about BREAST CANCER.

I would like to talk to women who have had breast cancer surgery and who decided:

1) not to have any or all of the suggested treatments (eg. chemotherapy, radiation or Tamoxifen)

OR

2) to stop breast cancer treatments.

To get more information about participating in this study, please contact

LOUANNE KEENAN

(780) 467-6471

or

lkeenan@ualberta.ca

(Please take a tab if you or anyone you know may be interested)

Breast Cancer Research
Louanne Keenan: (780) 467-6471
lkeenan@ualberta.ca

Breast Cancer Research
Louanne Keenan: (780) 467-6471
lkeenan@ualberta.ca

Breast Cancer Research
Louanne Keenan: (780) 467-6471
lkeenan@ualberta.ca

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APPENDIX E: INITIAL SORTING OF CATEGORIES

Health Care Providers

1. Family Doctor
2. Surgeon
3. Oncologists
4. Alternative Therapists
5. Conflict
6. Trust and Respect

Information System

1. Reading
2. Library
3. Internet
4. Health care provider
5. Reach to recovery/Survivors
6. Gut feeling

Support System

1. Family: Husbands/Siblings (sister/brother)/Mother/Father/Children
2. Friends
3. Health care providers
4. Reach to recovery/survivors

Side Effects

1. Surgery: lymphedema
2. Chemotherapy: chemopause
3. Radiation therapy
4. Tamoxifen
5. Psychological: concentration, sex

Personal Decision

1. Decision: Refusal / Confusion / Attitude / Knowing / Risk
2. Spirituality: coping
3. Causes of cancer

Advice to Women and Health Care Providers

Cancer and Death History

APPENDIX F: SECONDARY SORTING OF CATEGORIES

Searching for the Answers

1. Remembering cancer experiences

2. Speculating on the causes
   - Genetic predisposition
   - Hormonal interventions
   - Compromised immune system
   - Environmental toxins

3. Exploring the options
   - Limitations of the initial information
   - Investigation of the current information
   - Seeking information from others who can empathize

4. Reviewing the options with others
   - Health care specialists
   - Respected health care relationships
   - Getting the family on board

Listening to the Internal Dialogue

1. Body: Risk Factors
2. Mind: Psychological
3. Spirit: Spirituality

Actively Refusing

1. Coping
2. Altered perspective
3. Sharing with others

APPENDIX G: FINAL SORTING OF CATEGORIES

Establishing a Preference

1. Prescribed Medical Therapies
2. Alternative Interventions

Filling in the Gaps

1. Limitations of the initial information
2. Investigating the current information
3. Reviewing options with others
4. Getting the family "on board"

Listening to Internal Dialogue

1. Remembering other's cancer experiences
2. Speculating on the causes
3. Assessing body, mind, and spirit

Making a Decision "I Can Live With"

1. Persuasion
2. Conviction
3. Modification
4. Omission

APPENDIX H: ANALYSIS OF RESEARCHER'S INTERVIEW

RELATIONSHIPS

Self-discovery of lump: she informed her husband immediately. He remained supportive by accompanying her to her surgery and to several of her appointments. He tried to remain busy so the reality of the cancer would not be so evident.
Her sons did not like their mother telling everyone the same story about her cancer. She kept taking the boys to school and extra-curricular activities. This was in marked contrast to another woman she met who did not tell anyone other than her family.
Family members that were supportive included her two sisters and her five brothers who supported her decision to terminate the chemotherapy.
For the most part, she commented on the emotional and spiritual support of friends. She even had a friend who was a surgical nurse in the room adjacent to where she was going in for her surgery. Lots of friends were supportive with food, taking her dog for walks, assisting with rides, etc. Her dog was an important companion.

Some of her friends freaked out due to their ignorance concerning cancer. There were several things that frustrated her concerning well wishers:
They used the euphemism "situation" when they referred to breast cancer.
They came with advice concerning becoming a vegetarian.
They made comments like "Thanks for suffering for us."
She hated ignorant comments that the breast is only flesh, which was only said by people who have all of their flesh intact.

MEDICAL

She had a rapid diagnosis with mammogram and biopsy the day after she discovered the lump. The doctor diagnosed "cancer" from ultrasound and this was later confirmed after a biopsy.

The primary lumpectomy was under local anesthetic: she described this as a brutal experience. "Local anesthetic is an inhumane way to perform invasive surgery". She was appalled at the nurse's lack of sterile technique, but she was too exhausted at the time to defend her desire for sterile procedures. Days later when she contacted the hospital, the head nurse was condescending concerning her dental paranoia about contamination.

The surgeon told her over the phone that she had invasive cancer and needed more surgery. She was not impressed with the ridiculously short hospital stay. She

fainted and still had to go home. The emotional pain of having a second drain was painful and prolonged the agony.
She expressed frustration waiting 6 weeks for her appointment with the oncologists.

When she decided to terminate her chemotherapy, her oncologist tried to convince her to get the final three chemotherapy treatments once her blood counts improved. She still refused.
In contrast, the surgeon was glad that she quit chemotherapy and said he thought she didn't need the chemotherapy because the lymph nodes were not involved. The oncologists were concerned about the size of the tumor and the fact that it was invasive cancer.

REACH TO RECOVERY AND SUPPORT GROUP

Her initial contact with Reach to Recovery was frightening because the volunteer was very honest about the possibilities of breast cancer. Since then they have been a tremendous support.
One of the members of her breast cancer support group subsequently died from heart toxicity due to her chemotherapy. That woman also got burns from radiation and cancer in her lymphatic chain in her neck, her brain, and her other breast. Another woman in the group got a lung infection because of her lowered resistance to infection and a third woman had damage to her thyroid. She said that when she stopped going to the support group, she cried about the struggles with chemotherapy and the death of a dear friend.

DIFFICULTIES

There were numerous examples of her attempts to maintain her family commitments. Her oldest son had just turned 15; her youngest son was just finishing grade 6. She went to his graduation with a drain hanging out of her chest. She remained quite active and kept up with the household work and gardening.
She commented on the family photo that was taken the week before her mastectomy, when she still had two breasts.
She started a PhD program at the same time as she went for her 4th chemotherapy treatment. She was at a great disadvantage in comparison with her fellow students. She had to fit in studying when the nausea subsided. She arranged for her exams to be on the weeks when she did not have chemotherapy.

PERSONAL VIEWPOINT

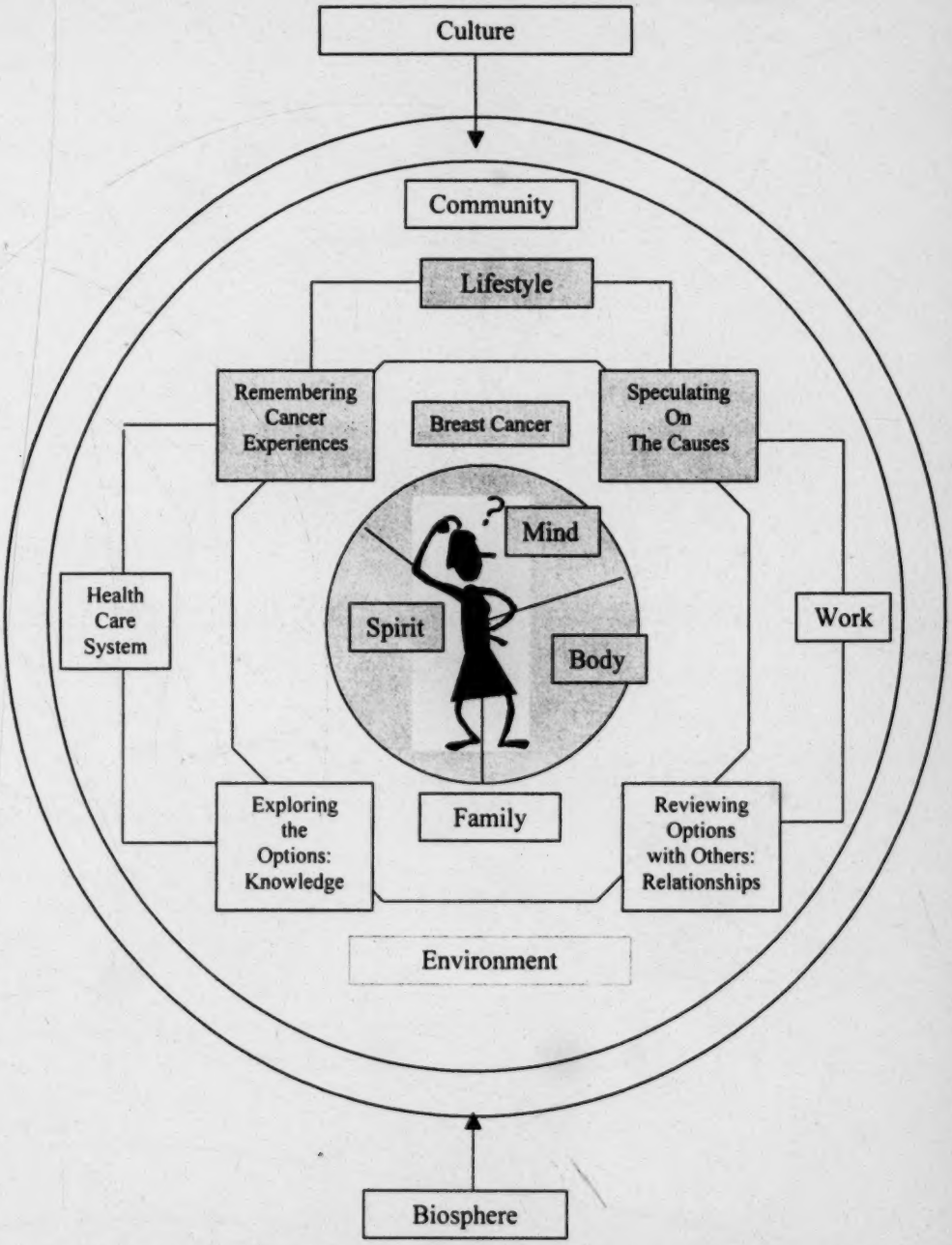
The realization that a mastectomy would leave her looking concave was overwhelming at first. Then she called a surgical nurse to get exact information about the procedure and to help make a decision concerning lumpectomy versus mastectomy. Three of her friends were experts on cancer and they gave her all the information they had collected. She decided to have a modified radical mastectomy after a phone call to her family doctor who explained the options once again after the surgeon.

She had a big lesson to learn about physical attractiveness and permanent disfigurement. She felt riddled with cancer every time she had a sore stomach or aching bones. Clothes became an issue and she expressed frustration with feeling fat and breastless. Her breast prosthesis did not arrive until 5 months after surgery. Finally she felt balanced and less fearful of movement of the prosthesis. Many of her plans for her future were put on hold. Holidays were compromised due to drug regime. After the decision to have a mastectomy she had to get additional information from friends and the library concerning cancer and chemotherapy treatments. She got her teeth cleaned prior to chemotherapy and told her employers she would be off for 6 months.
One month after finishing chemotherapy she was back at work as a dental hygienist and they had a celebration for her. Her doctor had warned her that her arm was compromised because the lymph nodes were gone and she should consider a new profession.

SIDE EFFECTS OF CHEMOTHERAPY

The chemotherapy drugs tasted bad and they made her arm cold as they went up into the veins in her arm. All of her hair fell out and she experienced severe dizziness and nausea. At the ninth chemotherapy she was doing poorly a school, and she was gaining weight due to the steroids she had to take. She had accumulated toxins in her body and she felt exhausted. After the second chemotherapy treatment she became menopausal and has experienced severe hot flashes ever since. She battles with osteoporosis.

TERMINATING CHEMOTHERAPY

Failing the blood tests and doing poorly on the exam at school made her want to quit both the chemotherapy and the courses. The low blood counts seemed to convince her that she would be betraying her body to add any more chemotherapy. The oncologist tried to convince her to finish the final three chemotherapy treatments once her blood counts improved. She still refused.

APPENDIX I: WOMEN'S INTEGRATIVE ECOLOGICAL SYSTEM